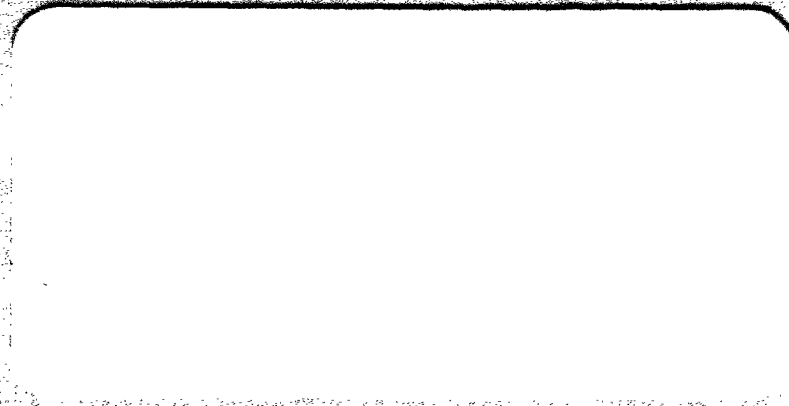


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Policy Research, Inc.

Contract No.: HHS-100-88-0035
MPR Reference No.: 7819
Contract Amount: \$424,854

DESIGN FOR A NATIONAL SURVEY
OF PERSONS WITH
DEVELOPMENTAL DISABILITIES:

PROTOTYPE INSTRUMENT

February 1990

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ACKNOWLEDGMENTS

The authors benefited incalculably from the advice and encouragement of many persons working in the areas of developmental disabilities and survey research. We would like particularly to thank the members of the project Technical Advisory Group who graciously and thoroughly answered our many questions and who helped to guide us through the myriad issues and programs affecting persons with developmental disabilities. We also benefited from the comments and support of the staff of the Division of Disability, Aging, and Long-Term Care in the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, particularly Robert Clark, Peg Porter, and Mary Harahan.

Jim **Conroy**, Brad Hill, Charlie Lakin, and Craig Thornton helped to shape our thinking about surveying persons with developmental disabilities and provided detailed suggestions for measuring functioning service use, and the other topics covered in the instrument. The staff at the National Center for Health Statistics kindly provided detailed information about the National Health Interview Survey and the ability to use that survey to screen the population for persons with developmental disabilities. Jack Feldman, Gerry Hendershot, Debbie Winn, and Peggy Barker gave particularly helpful advice. Other persons who provided background information **and** other valuable assistance include Barbara **Altman**, Earnie Bauman, G. **Loy** Ehlers, Paula Franklin, Ken **Manton**, Jack McNeil, **Malinda** Pavin, Robert **Schalock**, and Susan Ames Zerman.

We also would like to acknowledge the valuable contributions of Robin Albany, Lynne Beres, Stephanie Collins, Gloria **Gustus**, and Nancy Hennessey in helping to produce this report and prototype instrument.

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PART I: INTRODUCTION TO THE PROTOTYPE INSTRUMENT

This volume of the Final Report of the Project to Design a Survey of Persons with Developmental Disabilities presents the prototype instrument developed for the survey and provides, module by module and question by question, detailed description and analytic justification of the content of the instrument. This introduction discusses the purpose of the prototype instrument, describes the instrument development process, reviews remaining design issues, and defines various conventions used in the questionnaire. The second part of this paper presents **specific** justification for each question. The prototype instrument is contained in the third part.

A. PURPOSE OF THE PROTOTYPE INSTRUMENT

The instrument developed for the National Survey of Persons with Developmental Disabilities is considered a “prototype.” That is, it is the model for an actual survey instrument to be administered in such a survey. Organized into twenty-two modules, it contains individual questions recommended to measure key aspects of the characteristics and life circumstances of persons with developmental disabilities: demographic and household characteristics (including income and income supports,) living arrangements and characteristics of the residential setting, functional status in the seven life areas, formal service utilization, reimbursement sources and out-of-pocket expenses, informal support, and social interaction and behaviors. Table I.1 provides an outline of the contents of the prototype instrument.

The prototype instrument differs from an operational instrument in a number of ways. First, it is organized topically and screening questions intended for identifying persons eligible for the full survey are imbedded within a number of modules. It is recommended that the survey

TABLE I.1
INSTRUMENT MODULES

-
- A. LIVING ARRANGEMENTS/DEMOGRAPHICS**
 - B. RECEPTIVE/EXPRESSIVE COMMUNICATION**
 - C. LEARNING**
 - D. MOBILITY.**
 - E. SELF-CARE**
 - F. INDEPENDENT LIVING**
 - G. SELF-DIRECTION**
 - H EQUIPMENT/DEVICES**
 - I. EMPLOYMENT/EDUCATION/OTHER DAY ACTMTY**
 - J. CATEGORICAL CONDITIONS**
 - K. HEALTH STATUS**
 - L. MEDICAL AND HEALTH SERVICES**
 - M. MENTAL HEALTH SERVICES**
 - N. CASE MANAGEMENT SERVICES**
 - 0. FORMAL SUPPORT**
 - P. LIVE-IN FORMAL SUPPORT**
 - Q. INFORMAL SUPPORT**
 - R. SOCIAL INTERACTION/BEHAVIOR**
 - S. CHILD MODULE: DEVELOPMENTAL MILESTONES AND BEHAVIOR**
 - T. INCOME SUPPORT**
 - U. FACILITIES MODULE: FORMAL STAFF SUPPORT**
 - V. INTERVIEWER OBSERVATIONS**
-

will be implemented using the National Health Interview Survey (NHIS) as the mechanism for screening a national household sample to identify persons who are likely to be considered developmentally disabled. Therefore, the screening questions would be consolidated into a separate module for administration either as a supplement to the NHIS to identify persons for a later **followup** survey (the recommended approach), or as the first section of a supplement to screen persons who would continue with the remainder of the questions on the supplement. In either case, there would be a separate set of screening questions, affecting the structure of the remainder of the survey questions.

Secondly, while the prototype instrument does not contain extensive batteries of questions on every potential topic of interest to policy makers and researchers in the field of developmental disabilities, it covers a broad range of areas and contains a large number of questions. In fact, it is considerably too lengthy to be administered in its entirety as a supplement to the NHIS, and may be too lengthy even if administered as a separate **followup** survey. Therefore, some selection among modules and/or questions is likely to be necessary for operational purposes. The purpose of the prototype instrument was to provide a “menu” of the recommended measurement approaches and questions for a variety of topic areas. The final selection among these will depend upon the interests of the funding agencies and the priorities among various policy issues and research topics at the time the survey is implemented, as well as upon the resources available for the survey.

Further, the prototype instrument has been designed to address comparable issues for the entire developmentally disabled population, including young children and persons in various group and/or institutional living arrangements. This is another area that may be affected by the interests of the sponsoring agencies, the priorities among various policy and research goals, and/or

the level of funding available for the survey. If the focus of the survey were restricted to adults or to persons living in their own homes (with family or friends or on their own) or in small group settings (for example, those with fewer than 5 unrelated persons), certain modules of the prototype questionnaire would be inappropriate as would some response categories on other questions.¹

Finally, while the prototype instrument was developed following a rigorous and thorough process (as described in the next section), there are a number of measurement and other methodological issues that need further investigation. These include ensuring that both self and proxy respondents can understand and appropriately respond to the questions, investigating alternative wording to help reduce potential response errors, confirming that a reliable set of indicators have been developed for screening purposes, and developing a set of operational procedures to identify and interview proxy respondents when necessary. These issues and approaches to their resolution are discussed in Section C below.

Thus, while we expect the prototype instrument to provide both the framework for the operational instrument for the National Survey of Persons with Developmental Disabilities and to contain the majority of questions actually used in such a survey, final selection of modules and items within modules and the organization of the modules and questions will be made when the sponsorship and level of funding for the survey are known. In addition, some changes to the wording and format of questions may be made based upon further testing of the instrument, and operational procedures for identifying respondents and conducting the interviews must be specified.

¹On the other hand, if there is greater interest in group arrangements for persons with developmental disabilities, additional questions may be required to obtain information on characteristics of those arrangements.

B. DEVELOPMENT OF THE PROTOTYPE INSTRUMENT

The prototype instrument was produced after extensive review of available instrumentation and methodological literature and consultation with experts in the areas of substantive interest as well as in survey methodology. This section briefly describes the instrument development process.

The initial step in the development of the prototype instrument was to develop a list of core topic areas for which data on persons with developmental disabilities are desired. This list was initially developed based upon a review of the policy issues likely to affect this population and the concerns expressed by a recent working group of the U.S. Department of Health and Human Services (1988) about the lack of data upon which to base policy decisions. In addition to obtaining reliable estimates of the number of persons with developmental disabilities in various residential settings, detailed information on functioning, service use, and life experiences was desired. Based on discussions with the Technical Advisory Group, a list of core areas was developed (see Table 1.2).

The next step was to review existing instruments that contain measures in one or more of the core areas. A wide variety of instruments were identified and reviewed, including questionnaires from national statistical data collection efforts (such as the NHIS and the National Medical Expenditures Study, among others), instruments used in studies of specific populations similar to the target population for this survey (such as studies of persons with mental retardation), and clinical instruments developed for assessment of individuals with developmental disabilities. A full list of the instruments reviewed is contained in Table 1.3.

At the same time, the methodological literature was reviewed in key areas, including the reliability and validity of survey reports of health conditions, particularly embarrassing conditions,

TABLE I.2

CORE DATA CATEGORIES FOR THE NATIONAL SURVEY
OF PERSONS WITH DEVELOPMENTAL DISABILITIES

RESIDENTIAL ENVIRONMENT	FORMAL SERVICE USE
Types of Living Arrangements	Types of Services
Attributes/Institutional Character	Health and Medical
Residential History (Quality)	Other Formal Services
	Equipment/Aides
	Quantity of Services
	Need for Services
	Payment for Services
DEMOGRAPHIC CHARACTERISTICS	Insurance Coverage
Age	Source of Payment
Sex	Out-of-Pocket Expenditures
Race	(Satisfaction with Services)
Marital Status	
Family Structure (household composition)	PROVISION OF INFORMAL SUPPORT
Income (individual and household)	Types of Support/Assistance (including financial contributions)
Participation in Federal Programs	Quantity of Support/Assistance (Caregivers' Experiences and Attitudes)
Educational Attainment	
Identifiers	
FUNCTIONAL LIMITATIONS	
Types of Limitations	CATEGORICAL CONDITIONS
Self-care	Conditions
Language	Primary diagnosis
Learning	Other diagnoses
Mobility	Health Status
Self-direction	
Independent Living	
Economic Self-sufficiency	
Adaptive/Maladaptive Behavior	EMPLOYMENT STATUS
Severity of Limitations	Labor Force Status
Age of Onset	Type/Level of Support
	Hours/Earnings

TABLE I.2 (continued)

SOCIAL INTERACTION/INTEGRATION	(PARTICIPATION IN OTHER REGULAR DAILY ACTIVITIES)
Frequency/Location/type of interactions	
Transportation mode/problems	(SUBJECTIVE WELL-BEING)
Decision making	
Maladaptive behaviors	

Items in parentheses were deemed to have secondary priority for this design effort.

TABLE I.3

INSTRUMENTS REVIEWED IN DEVELOPING THE PROTOTYPE INSTRUMENT

National Health Interview Survey (1980-89); National Center for Health Statistics.

Census Disability Survey; U.S. Department of Commerce, Bureau of the Census.

National Medical Expenditure Survey, National Center for Health Services Research.

Inventory for Client and Agency Planning (**ICAP**); Available through DLM Teaching Resources, Allen, Texas 75002.

Client Development Evaluation Report (CDER); State of California, Department of Developmental Services, Health and Welfare Agency.

National Survey of Consumers of Services for Individuals with Developmental Disabilities; Temple University/The National Association of DD Councils.

A Managed Care Program for Working-Age Persons with Physical Disabilities; Office of Research, National Rehabilitation Hospital.

Access Wilmington Handicapped Survey; City of Wilmington, Delaware, Mayor's Office of Community Affairs.

National Maternal and Infant Health Survey (Proposed 1990 Longitudinal Follow-up); U.S. Department of Health and Human Services.

Survey of Income and Program Participation (**SIPP**)--1984 Wave 3 (Disability); U.S. Department of Commerce, Bureau of the Census.

1978 Survey of Disability and Work; Social Security Administration.

Clinical Adaptive Behaviors Inventory; State of New Jersey, Division of Developmental Disabilities.

Minnesota Longitudinal Study; Research and Training Center on Community Living, University of Minnesota.

The Uniform Data Set for Medical Rehabilitation; SUNY Buffalo, Research Foundation.

Behavior Development Survey; Temple University, Developmental Disabilities Center.

The ICD Survey of Disabled Americans--Bringing Disabled Americans into the Mainstream; Conducted for the International Center for the Disabled by Louis Harris and Associates,

TABLE I.3 (continued)

Medicare Alzheimer's Disease Demonstration and Research Project; **Mathematica** Policy Research, Inc.

Structured Training and Employment Transitional Services; Follow-up Survey: **Mathematica** Policy Research, Inc.

Transitional Employment Training Demonstration, Follow-up **Survey**; **Mathematica** Policy Research, Inc.

of health-related events such as medical care utilization, and of functioning status, particularly disability status. The literature on the use of proxy respondents was also reviewed, as it is expected that many if not most of the interviews for the National Survey of Persons with Developmental Disabilities would be conducted with another person, in addition to (or instead of) the developmentally disabled individual. (The bibliography appended to this volume contains citations to the literature in these methodological areas.) The methodological literature was used to **identify** potential measurement problems associated with key data items for the survey and solutions that had been found to be effective in other studies, particularly in other large national studies.

Next, a discussion paper was prepared for each data topic identified as a core item for the survey. Each paper reviewed the data topic focusing on the dimensions or elements to be measured and the analytic purposes for the data, discussed methodological and measurement issues particularly associated with the data topic, provided an overview of measurement approaches used in other instruments, and presented a set of recommendations for questions and response categories to measure the various data elements. These discussion papers were distributed to various members of the Technical Advisory Group and to other experts to be reviewed and a summary of the recommendations was presented and discussed at a meeting of the Group.

Comments on measurement approaches and particular survey questions and response categories were compiled from the reviewers and used in the preparation of a draft instrument. This draft instrument was then circulated for further comment at the same time a small pretest was conducted.

A total of eight individuals were selected for the pretest, including persons known to be mentally retarded, some with another condition that may be, associated with developmental disabilities (cerebral palsy), and others with a physical impairment (loss of limb) acquired late in what is usually considered the developmental period. The selected individuals generally acted as self-respondents, although parents and staff members were also interviewed as proxies. The pretest was used to estimate the average length of the interview (about 90 minutes, ranging up to 2.5 hours), to identify questions that were difficult for respondents to understand, and to determine whether responses to the survey were consistent with what was known about the individual from external sources (for example, that he/she was in a supervised apartment or in a sheltered workshop, or that he/she had been diagnosed with mental retardation).

The comments from reviewers and the results of the small pretest were used in making final revisions to the prototype instrument, which is contained in Part III of this volume. Not all comments and concerns were able to be completely resolved and some of the issues raised during the development process have been identified as particular areas needing further investigation.

C. REMAINING DEVELOPMENT ISSUES

Four issues in particular should be addressed further in the development of the instrument, other than those associated with questionnaire length and coordination with the **NHIS** which were discussed earlier. The remaining four issues are:

- o Reliability and accuracy of the screening criteria
- o Identification of appropriate proxy respondents
- o Identification of categorical conditions and disability status
- o Measurement of key service use

This section briefly reviews these issues and suggests approaches for their resolution.

1. Reliability and Accuracy of the Screening Criteria

The proposed screening criteria (based on limitations in functioning, categorical conditions, and use of selected services) are reviewed in detail in an accompanying report (Thornton, et al., 1990). The specific items and response categories proposed to operationalize the screening criteria are indicated on the prototype instrument. However, a number of issues remain with regard to these criteria. The screening criteria must be able to be administered reliably in the survey format. Furthermore, if the NHIS is used as the screening vehicle, the screening questions must fit into a larger household survey in which proxy respondents are used extensively. Even more importantly, further information is needed on the extent to which the criteria as operationalized on the prototype instrument accurately identify persons who would be considered developmentally disabled based on more complete clinical data. It is important that the operational criteria screen in all or virtually all individuals **who** would be considered developmentally disabled. For that reason, the screening criteria proposed in the design and the prototype instrument are very inclusive. But it is also important for operational and budget reasons that the screening criteria not inappropriately include large numbers of persons who would not meet any likely definition of developmental disabilities (for example, who have only a mild disability or one that is associated with aging).

These concerns suggest that two kinds of further development work are needed with regard to the screening criteria. First, it will be necessary to conduct interviews with a sample of persons for whom external data are available on the key elements of the screening criteria and who could be classified a priori as having different degrees or types of developmental disabilities. Analyses of the match between classifications of individuals based on responses to

survey questions and those based on external evidence will identify potential groups that may be underrepresented in the survey because of measurement problems. A second type of study would involve administration of the screening questions to a diverse group of persons, including individuals who would not be considered developmentally disabled under any criteria. Here the focus would be on determining whether the screening criteria are too inclusive. Both types of analyses would be supported by a pilot test that interviewed a sample of households that had been “seeded” to include some persons known to be developmentally disabled (interviewers would have no knowledge of the status of sample members prior to the interview). A pilot test is essential to ensure that the screening criteria appropriately classify individuals, that is the screening produces very few “false negatives” (that is, developmentally disabled persons who are not identified by the survey) while keeping the number of “false positives” to a minimum.

Under the recommended scenario in which the screening questions are included as a supplement to NHIS and the remainder of the questions are administered as a **followup** survey, it will be possible to **finetune** the selection of sample. In particular, analyses on data collected on the supplement could be conducted to find the sample that best preserves the full set of persons likely to be determined to have developmental disabilities and minimizes the number of other individuals who might pass the broadest set of screening criteria. For example, it may be more efficient and equally reliable to require that only persons with two or more functional limitations be included in the **followup** survey, rather than any person with a functional limitation. Within the time that would normally elapse between the administration of the NHIS supplement and of the **followup** survey, there should be sufficient opportunity for some of these analyses to be conducted.

2. Identification of Appropriate Proxy Respondents

Because many individuals in the target population will have cognitive impairments and some will also have substantial communication limitations, it is expected that proxy respondents will be interviewed for a large proportion of the sample. This section discusses some of the issues concerning the identification and use of proxy respondents that need further investigation.

There are three circumstances in which the issue of proxy respondents is relevant in the National Survey of Persons with Developmental Disabilities. First, assuming that the NHIS is used as a vehicle for administering at least the screening questions for the survey, the proxy respondents used in the **NHIS** will provide some key information on other related household members. Proxy respondents are permitted in the **NHIS** for children and for individuals who are away from the household at the time of the interview or who are otherwise unable to participate in the interview, provided that the proxy is an adult (age 17 or older) who is related to the individual about whom they are reporting. Second, proxy respondents will be necessary or advisable in the **followup** survey for screened household sample members who have substantial cognitive, or communication limitations. Thirdly, proxy respondents will probably be used frequently among the sample of persons drawn from the supplemental facility sample frame, both because that sample is likely to include more substantially impaired persons and because contact with staff members will be necessary to arrange access to sample members.

No matter under what circumstances a proxy respondent is used, there are concerns about the accuracy and completeness of proxy responses. There have been a number of studies of proxy response particularly with regard to health conditions, health events, and health-related service use, with mixed conclusions. For example, in some studies (Kovar and Wright, 1973; Haase and Wilson, 1972; White and Massey, 1981; Miller et al., 1986) proxies have been found to underreport health events (such as illnesses) and health care utilization compared to self-

reports, while others (Anderson et al., 1979; Cannell and Fowler, 1963) found no significant differences. On the particular issue of reports of stigmatizing physical and mental conditions, there is also conflicting evidence; Miller et al. (1986) found that the agreement between self and proxy reports of such conditions was lower than for other conditions, while Berk et al., (1982) concluded that the proxy reports can be closer to physician reports than are self-reports of stigmatizing health conditions.

The lack of consistent findings of response biases associated with using proxy respondents, combined with other evidence of significant response errors associated with self-reports from persons with mental retardation (Sigelman, 1980, 1981, and 1982; Stephens, 1984), supports the proposed design which presumes proxy responses. However, a more definitive study of the effects of proxies on responses, with the target population and key measures from the prototype instrument, would be desirable and could be included in pilot tests of the screening instrument.

3. Identification of Categorical Conditions and Disability Status

As noted above, there can be underreporting of stigmatizing conditions on surveys, particularly when self-reports are relied upon. In particular, mental illness and mental retardation are often not reported by individuals known to have these conditions (see Koegel and Edgerton, 1982; Marquis et al., 1981)², and proxy reports do not always solve this problem of underreporting. Without external sources (such as clinical records or contact with agencies serving respondents), it is likely that the survey estimates will undercount the proportion of persons with developmental disabilities who are mentally retarded.

²This finding was replicated among the mentally retarded pretest respondents interviewed for this **project**.

In addition to problems identifying persons with particular stigmatizing conditions, reports of disability status, particularly in the area of work-related disability, can be affected by a number of factors, including differences in expectations regarding capacity and work experiences among persons of different ages (Haber, 1970; Greenblum, 1984), from different cultural backgrounds (Linn et al., 1980), of different economic circumstances (Chirikos and Nestel, 1984), and in different work environments (Nagi, 1976; Luft, 1978; Yelin et al., 1980).

These problems of accurate reports of categorical conditions and functional disabilities are critical, not only to the estimation of key subgroups and description of important aspects of individual life circumstances, but also to the successful operationalization of the screening criteria for the survey. The pilot test recommended earlier would help assess the extent of these problems in the target population, and suggest ways to modify questions and procedures that may help alleviate them.

4. Measurement of Key Service Use

Another area in which accurate data may be difficult to obtain, from either self or proxy reports, is in the identification of key services. Such services for the developmentally disabled population include supported employment and community-based residential arrangements and case management. By intent these services are designed to be as unobtrusive as possible and in many cases to transition the individual to a life style as close to the norm as possible. In addition, these services or programs may be known by a variety of local names and individuals may not identify the services per se, but think of the individuals or specific agency with whom they have contact. Therefore, it is likely to be difficult for respondents to indicate whether they receive these types of services. This issue is of concern in its potential impact on screening as well as on estimates of current service use.

Again, a pilot test with individuals about whom service use patterns are known would be helpful in assessing the extent and potential impact of these reporting errors and perhaps in devising alternative wording that may aid accurate and complete reports. However, without access to agencies and/or program records as part of the survey, such errors are likely to remain to some extent.

D. CONVENTIONS USED IN PROTOTYPE INSTRUMENT

The following conventions have been used in the prototype instrument:

- All capitals are used for instructions to the interviewer and for response categories which are not to be read to the respondents
- The questions have been worded for self-respondents, with alternative wording provided for proxy respondents
- Alternative words or phrases, to be read as appropriate, are shown in parentheses
- Interviewer skip instructions are generally found in parentheses after the numeric response code on the right hand side of the page
- Interviewer checkboxes are included and are given question numbers in the instrument; these are not read to the respondents but are used by the interviewer in determining appropriate paths through the questionnaire
- Certain questions are asked only of persons in particular age ranges or who meet other qualifications; an interviewer **checkbox** is generally provided prior to these questions which skip inappropriate respondents to other questions
- In some questions with lists of response categories, an “Other” response is allowed with the instruction that the interviewer is to probe and record the nature of the other response
- In questions with lists of response categories, there is generally an instruction at the top of the list indicating whether only one or more than one response is allowed
- Screening questions are marked (S) before the question number, with the response categories which would identify an individual for the **followup** survey indicated with an asterisk

- o Questions which appear in identical form on the NHIS Core Questionnaire are marked (C) before the question number

E. OVERVIEW OF REMAINING SECTIONS

Part II of this volume contains a description of each module of the prototype instrument, including an overview of the purpose of the module and a question-by-question discussion of each item's analytic purpose, notes on administration of the question (for example, reference period, whether it is a screening item, what age range is applicable), and the source for the item if it was adopted or adapted from a particular instrument.

Part III of this volume contains the prototype instrument.

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PART II: QUESTION JUSTIFICATION

MODULE A: LIVING ARRANGEMENTS/DEMOGRAPHICS

This section obtains demographic and household information and determines the type of living arrangement, including type of group residence, if applicable, and housing costs. Additional questions on staffing, services provided, and other characteristics of group residences are obtained in various sections throughout the interview and in a special section (U) at the end of the interview. (To some extent, the type of residence will be known from the sample frame used--NHIS household survey or supplemental facility sample.) The data on demographic household, and residential characteristics will be used in descriptive analyses and to create subgroups for analysis.

A1,A3-A4 Brief Description: Household Composition

Analytic Purpose: Obtains information on household composition which is used in demographic analyses. Also provides information on formal live-in staff.

Other Notes: **The** target sample member will be known from the NHIS screening survey if this instrument is administered as the **followup** survey. Otherwise, all questions are asked of all individuals in the household or residence if a group facility. (Samples may be drawn within large group facilities.)

Source: NHIS Core Question (A1, with additional response categories)

A5a-b Brief Description: Type of Group Residence

Analytic Purpose: Determines from respondent's report the type of group facility, if any.

Other Notes: Screening question; persons currently living in supervised group residences (including supervised apartment) would be eligible for **followup** survey, if began living there prior to age 50. (It is assumed that persons who begin in such residences at an older age do so because of limitations associated with aging or with impairments acquired in adulthood.)

MODULE A: **LIVING** ARRANGEMENTS/DEMOGRAPHICS (continued)

A5c-e	<p><u>Brief Description:</u> Reimbursement Source and Out-of-Pocket Expenses for Supervised Residences</p> <p><u>Analytic Response:</u> Used to construct measure of public and private costs for services utilized by DD persons.</p> <p><u>Other Note:</u> Asked only of persons currently living in a supervised group residence.</p>
A6	<p><u>Brief Description:</u> Ownership Status</p> <p><u>Analytic Purpose:</u> Determine assets and whether any housing costs (mortgage or rent) are paid.</p> <p><u>Other Notes:</u> Asked only of persons not living in supervised group residences.</p> <p><u>Source:</u> Modified from 1980 Census of Population and Housing.</p>
A7-A9	<p><u>Brief Description:</u> Housing Costs</p> <p><u>Analytic Purpose:</u> Amount of monthly mortgage, rent, or fees and what is included in these monthly charges are used to describe total housing costs. Information of services covered in rent also assists in categorization of type of living arrangement.</p> <p><u>Source:</u> Modified from 1980 Census of Population and Housing.</p>
A10	<p><u>Brief Description:</u> Participation in Residential Decisions</p> <p><u>Analytic Purpose:</u> Used to describe level of functioning in area of Self-Direction, and receipt of case management through agency.</p> <p><u>Other Notes:</u> Applicable to persons age 18 or older.</p>
A11a	<p><u>Brief Description:</u> Waiting Lists for Group Residence</p> <p><u>Analytic Purpose:</u> Used to assess unmet demand for residential services.</p>

MODULE A: LMNG ARRANGEMENTS/DEMOGRAPHICS (continued)

A11b-d	<p><u>Brief Description:</u> Previous Residence in Supervised Group Facility</p> <p><u>Analytic Purpose:</u> Determines whether ever institutionalized and whether ever received supervised residential services.</p> <p><u>Other Notes:</u> Screening question; persons previously living in supervised group residences, (including supervised apartment) would be eligible for followup survey, if began living there prior to age 50. (It is assumed that persons who begin living in such residences at an older age do so because of limitations associated with aging or with impairments acquired in adulthood.)</p>
A12	<p><u>Brief Description:</u> Education Completed</p> <p><u>Analytic Purpose:</u> Used in demographic analyses.</p> <p><u>Source:</u> Q.A12a from NHIS Core Question.</p>
A13-14	<p><u>Brief Description:</u> Race/Ethnic@</p> <p><u>Analytic Purpose:</u> Used in demographic analyses.</p> <p><u>Source:</u> NHIS Core Question.</p>
A15	<p><u>Brief Description:</u> Marital Status</p> <p><u>Analytic Purpose:</u> Used in demographic analyses.</p> <p><u>Source:</u> NHIS Core Question.</p>
A16	<p><u>Brief Description:</u> Household Income</p> <p><u>Analytic Purpose:</u> Used in demographic analyses.</p> <p><u>Source:</u> NHIS Core Question.</p>

MODULE B: RECEPTIVE/EXPRESSIVE COMMUNICATION

This section obtains information on functioning in the area of receptive and expressive communication. It includes questions designed for screening on a national household survey (questions B2 and **B5**). The questions in this section will be either asked of a proxy respondent or answered by the interviewer on the basis of personal observation. Self-respondents will not be asked these questions.

B1 Brief Description: Mode of Expressive Communication

Analytic Purpose: Used to describe mode of functioning and use of assistive devices.

Other Notes: This section to be completed with proxy respondent or by interviewer observation.

Source: Adapted from NCHS Minimum Data Set.

B2 Brief Description: Adequacy of Expressive Communication for Needs

Analytic Purpose: Used to describe level of functioning.

Other Notes: Screening question; persons reporting any difficulty would be eligible for the **followup** survey, dependent upon age.

Source: Temple Behavior Development Survey.

B3 Brief Description: Adequacy of Expressive Communication for Thoughts or Ideas

Analytic Purpose: Used to describe level of functioning.

Other Notes: Screening question; persons reporting any difficulty would be eligible for the **followup** survey, dependent upon age.

Source: Temple Behavior Development Survey.

MODULE B: RECEPTIVE/EXPRESSIVE COMMUNICATION (continued)

- B4 Brief Description: Mode of Receptive Communication
- Analytic Purpose: Used to describe level of functioning and use of assistive devices.
- Source: Adapted from NCHS Minimum Data Set.
-
- B5 Brief Description: Adequacy of Receptive Communication
- Analytic Purpose: Used to describe level of functioning.
- Other Notes: Screening question; persons reporting any difficulty would be eligible for the **followup** survey, dependent upon age.
- Source: Temple Behavior Development Survey.

MODULE C: LEARNING

This section obtains information on functioning in the area of learning. It focuses on reading, writing, and quantitative reasoning skills, as well as determining current participation in special education or needs or limitations in school attendance. The questions on special education and school attendance, taken **from** the NHIS Core Questionnaire, are screening items for the purpose of identifying members of a national household sample eligible for a **followup** survey. This module is asked only of individuals age 5 or older. Questions on early intervention services for younger children are included in Module M, questions **M3-M5**.

- Clb Brief Description: Ability to write or use other mode of conveying information by use of written language
- Analytic Purpose: Used to describe level of functioning, dependent upon age.
- Other Notes: Applicable to persons age **5** or older.
- Source: Temple Behavior Development Survey.
-
- C2 Brief Description: Ability to read
- Analytic Purpose: Used to describe level of functioning, dependent upon age.
- Other Notes: Applicable to persons age 5 or older.
- Source: Temple Behavior Development Survey.
-
- c3 Brief Description: Ability to perform arithmetic calculations
- Analytic Purpose: Used to describe level of functioning, dependent upon age.
- Other Notes: Applicable to **persons** age 5 or older.
- Source: Temple Behavior Development Survey.

MODULE C: LEARNING (continued)

C5-C8	<u>Brief Description:</u>	School attendance as affected by health or impairment
	<u>Analytic Purpose:</u>	Used to describe limitations in usual life activities for children.
	<u>Other Notes:</u>	Screening questions (C5-C8); persons prevented from or limited in attending school or needing special class or school would be eligible for followup survey. Applicable to persons age 5-17.
	<u>Source:</u>	NHIS Core Questions (excluding C5a).
C9	<u>Brief Description:</u>	Condition associated with limitations in school attendance.
	<u>Analytic Purpose:</u>	Used to describe conditions causing limitations in usual life activities for children.
	<u>Other Notes:</u>	Applicable to persons age 5-17.
	<u>Source:</u>	NHIS Core Questions.

MODULE D: MOBILITY

This section obtains information on functioning in the area of mobility, including lifting and carrying, inside and outside mobility, and use of stairs. These questions are asked of persons age 5 or older. Difficulty or inability to move around inside, outside, or on stairs are used as screening criteria for the **followup** survey. Persons age 16 or older are asked about ability to drive a car and to use public transportation with or without assistance or modifications.

D2	<p><u>Brief Description:</u> Ability to lift and carry 10 pounds</p> <p><u>Analytic Purpose:</u> Used to describe strength which is associated with capacity to perform various manual tasks.</p> <p><u>Other Notes:</u> Applicable to persons age 5 or older.</p> <p><u>Source:</u> Based upon questioning techniques used in ICAP, the Census Disability Add-on, and SIPP.</p>
D3-D4	<p><u>Brief Description:</u> Difficulty with inside mobility, with and without assistance or equipment</p> <p><u>Analytic Purpose:</u> Used to describe level of functioning.</p> <p><u>Other Notes:</u> Applicable to persons age 5 or older.</p> <p>Screening question; persons unable to perform activity or perform with difficulty with assistance would be eligible for followup survey.</p> <p><u>Source:</u> Census Disability Add-on.</p>
D5-D6	<p><u>Brief Description:</u> Difficulty with stairs, with and without assistance or equipment</p> <p><u>Analytic Purpose:</u> Used to describe level of functioning.</p> <p><u>Other Notes:</u> Applicable to persons age 5 or older.</p> <p>Screening question; persons unable to perform activity or perform with difficulty with assistance would be eligible for followup survey.</p> <p><u>Source:</u> Census Disability Add-on.</p>

MODULE D: MOBILITY (continued)

D7-D8	<u>Brief Description:</u>	Difficulty with outside mobility, with and without assistance or equipment
	<u>Analytic Purpose:</u>	Used to describe level of functioning.
	<u>Other Notes:</u>	Applicable to persons age 5 or older. Screening question; persons unable to perform activity or perform with difficulty with assistance would be eligible for followup survey.
	<u>Source:</u>	Census Disability Add-on.
D10	<u>Brief Description:</u>	License or permit to drive
	<u>Analytic Purpose:</u>	Indicates self-direction as well as degree of independence in transportation.
	<u>Other Notes:</u>	Applicable to persons age 16 or older.
D11	<u>Brief Description:</u>	Ability to drive car with or without modifications
	<u>Analytic Purpose:</u>	Indicates degree of independence in transportation.
	<u>Other Notes:</u>	Applicable to persons age 16 or older.
D12-D13	<u>Brief Description:</u>	Use of public transportation, with or without assistance
	<u>Analytic Purpose:</u>	Used to describe level of functioning.
	<u>Other Notes:</u>	Frame of reference = past month.
	<u>Source:</u>	Census Disability Add-on.

MODULE E: SELF-CARE

This section obtains information on functioning in the area of self-care (often referred to as “activities of daily living” or ADL tasks). These activities or tasks include eating, bed/chair transfer, dressing, bathing, taking medications, and toileting (including managing a catheter or colostomy bag). Persons needing reminders or assistance in any of these tasks would be screened eligible for the **followup** survey, depending upon their age. This section also contains questions on use of special equipment in these tasks and frequency of urinary and bowel incontinence.

- | | |
|------|--|
| E1 | <p><u>Brief Description:</u> Performance of ADL tasks (eating, bed/chair transfer, dressing, bathing) with or without assistance or equipment</p> <p><u>Analytic Purpose:</u> Used to describe level of functioning, dependent upon age.</p> <p><u>Other Notes:</u> Screening question; persons needing human assistance would be eligible for followup survey, dependent upon age.</p> <p>Reference period = past week.</p> <p><u>Source:</u> Medicare Alzheimer’s Disease Demonstration and Research Project.</p> |
|
 | |
| E2 | <p><u>Brief Description:</u> Administration of prescription medication, with or without assistance</p> <p><u>Analytic Purpose:</u> Used to describe level of functioning, dependent upon age.</p> <p><u>Other Notes:</u> Screening question; persons needing human assistance would be eligible for followup survey, dependent upon age.</p> <p>Reference period = past week.</p> |

MODULE E: SELF-CARE (continued)

- E3-E4** **Brief Description:** Mode of care of urinary and bowel needs
- Analytic Purpose:** Indicates special equipment used in toileting.
- Other Notes:** Persons using bedpans or diapers only are assumed to depend upon assistance in toileting; used as screening question dependent upon age.
- Reference period = past week.
-
- E5** **Brief Description:** Receipt of assistance in toileting
- Analytic Purpose:** Determines whether assistance needed in toileting, for persons using standard or modified toilet, and/or in managing catheter or colostomy bag.
- Other Notes:** Used as screening question, dependent upon age.
- Reference period = past **week**.
-
- E6-E7** **Brief Description:** Frequency of urinary and bowel accidents
- Analytic Purpose:** Measures frequency of incontinence; used to describe level of functioning.
- Source:** The **1990** Longitudinal **Followup** to the National Maternal and Infant Health Survey.

MODULE F: INDEPENDENT LIVING

This section obtains information on functioning in the area of independent living (often referred to as “instrumental activities of daily living” or IADL tasks). These activities or tasks include preparing meals or snacks, doing light housework, grocery shopping, doing laundry, and using the telephone). This section is asked only of persons age 12 or older and allow individuals to respond that they do not do the activity because it is provided as part of residential services or for other reasons. Information on the use of special equipment is also obtained. Persons indicating use of human assistance on these activities would be screened eligible for the **followup** survey.

F2	<u>Brief Description:</u>	Performance of IADL tasks (meal preparation, housekeeping, grocery shopping, laundry), with or without assistance or equipment
	<u>Analytic Purpose:</u>	Used to describe level of functioning, dependent upon age.
	<u>Other Notes:</u>	Applicable to persons age 12 or older. Screening question; persons needing assistance on these tasks , would be eligible for follow-up survey.
	<u>Source:</u>	Medicare Alzheimer’s Disease Demonstration and Research Project.
F3-F5	<u>Brief Description:</u>	Use of telephone, with or without assistance
	<u>Analytic Purpose:</u>	Used to describe level of functioning, dependent upon age.
	<u>Other Notes:</u>	Applicable to persons age 12 or older. Screening question; persons needing assistance in looking up telephone numbers would be eligible for followup survey.

MODULE F: INDEPENDENT LIVING (continued)

F6 **Brief Description:** Condition and age of onset of condition associated with **funcational** limitations

Analytic Purpose: Used to describe health conditions associated with limitations.

Other Notes: Refers to functional limitations in mobility, self-care, and independent living -- the screening questions in those modules would determine eligibility for the **followup** survey **if** the main condition associated with the functional limitations **occured** prior to age 22.

Source: **NHIS** Core Question.

MODULE G: SELF-DIRECTION

This section obtains information on functioning in the area of self-direction. Additional measures of self-direction are found in Sections A (Living Arrangements/Demographics), I (Employment/Education/Other **Day Activity**), and R (Social Interaction Behavior) (independence in decision-making); E (Self-Care), F (Independent Living); 0 through Q (Formal and Informal Support) (need for supervision), and T (Income Support) (representative payee for Social Security checks). This section is asked only of persons age 18 or older, and contains questions on guardianship and consent as well as on independence in handling money. All are used as screening criteria to determine eligibility for the follow-up survey.

G2	<u>Brief Description:</u>	Legal guardianship
	<u>Analytic Purpose:</u>	Determines whether a legal guardian has been appointed by the court.
	<u>Other Notes:</u>	Applicable to persons age 18 or older. Screening question; persons 18 or older with legal guardian are eligible for followup survey.
G3-G4	<u>Brief Description:</u>	Consent for medical care
	<u>Analytic Purpose:</u>	Determines whether the individual is considered able to give consent for medical care.
	<u>Other Notes:</u>	Applicable to persons 18 or older. Screening question; persons 18 or older who do not give own consent are eligible for followup survey.
	<u>Source:</u>	Adapted from the National Consumer Survey.

MODULE G: SELF-DIRECTION (continued)

G5-G11 **Brief Description:** Money handling with or without assistance

Analytic Purpose: Determines whether the individual handles **financial** transactions (shopping, bill paying, banking) independently.

Other Notes: Applicable to persons age 18 or older.

Screening questions; persons 18 or older who do not select own items when shopping, have help budgeting their money, have help depositing or withdrawing money from a bank, or must have checks co-signed are eligible for **followup** survey.

MODULE H: EQUIPMENT/DEVICES

This section obtains information on the use of and out-of-pocket costs for special equipment. Equipment mentioned in previous questions can be coded here without asking. This section also obtains information on modifications in the residential environment that may be needed to accommodate an individual's physical or sensory disabilities. These items are measures of the support needed to assist developmentally disabled persons to live as independently as possible.

- H1** Brief Description: Equipment or devices currently or regularly used
- Analytic Purpose: Asked primarily as lead-in to question on costs, as use of specific equipment associated with functioning obtained in previous sections.
- Other Notes: May be coded without asking if known from responses to previous questions.
-
- H3,H5** Brief Description: Out-of-pocket expenses for equipment
- Analytic Purpose: Total costs to individual or family of durable equipment (e.g., wheelchair) and costs over **12-month** period for other equipment or supplies (e.g., diapers).
-
- H6,H8** Brief Description: Structural modifications in current residence and whether residence selected or remodeled specifically for those modifications
- Analytic Purpose: Used to describe residential environment and to indicate type of housing required for persons with developmental disabilities.
- Source: List adapted from the 1978 Survey of Disability and Work.

MODULE H: EQUIPMENT/DEVICES (continued)

H9	<table><tr><td data-bbox="431 308 660 351"><u>Brief Description:</u></td><td data-bbox="683 308 1476 393">Whether any financial assistance received by individual or family for making modifications</td></tr><tr><td data-bbox="431 414 660 457"><u>Analytic Pumose:</u></td><td data-bbox="683 414 1476 534">Indicates whether any costs of modifications borne by individual or family, to help construct measures of public and private expenditures.</td></tr></table>	<u>Brief Description:</u>	Whether any financial assistance received by individual or family for making modifications	<u>Analytic Pumose:</u>	Indicates whether any costs of modifications borne by individual or family, to help construct measures of public and private expenditures.
<u>Brief Description:</u>	Whether any financial assistance received by individual or family for making modifications				
<u>Analytic Pumose:</u>	Indicates whether any costs of modifications borne by individual or family, to help construct measures of public and private expenditures.				

MODULE I: EMPLOYMENT/EDUCATION/OTHER DAY ACTIVITY

This section obtains information on usual major activity, including employment, education, training, and other day activities such as keeping house or participating in a day program. A number of these items are from the NHIS Core Questionnaire and can be used for direct comparison with national statistics on limitations in major life activities. Other questions can be used to calculate labor force participation in ways comparable to those for other national statistics.

12-13 Brief Description: Whether individual's own income is sufficient for basic needs and for additional expenses

Analytic Purpose: Description of adequacy of income, based on self/proxy perception

Other Notes: Applicable to persons 16 years or older.
Reference period = last week

Source: University of Minnesota RRTC instrument.

14 Brief Description: Current Employment Status

Analytic Purpose: Used to indicate major life activity as basis for questions on limitations

Other Notes: Applicable to persons age 16 or older.

Source: **NHIS** Core Question.

I5-I9 Brief Description: Limitations in employment, kind or amount of work, or housework (if applicable)

Analytic Purpose: Used to indicate degree and type of limitations in major life activities for adults and conditions associated with limitations.

Other Notes: Screening questions; persons **with** limitations in employment (or housework) associated with DD conditions and/or those **occurring** prior to age 22 would be eligible for **followup** survey. Applicable to persons 16 years or older (NHIS restricts to age 17 or older).

Source: NHIS Core Questions.

MODULE I: EMPLOYMENT/EDUCATION/OTHER DAY ACTIVITY (continued)

110-111	<p><u>Brief Description:</u> Employment/Job Search Activities</p> <p><u>Analytic Purpose:</u> Measures labor force participation.</p> <p><u>Other Notes:</u> Applicable to persons age 16 or older. Reference period = past 2 weeks.</p> <p><u>Source:</u> Based upon SIPP</p>
113	<p><u>Brief Description:</u> Number of current jobs</p> <p><u>Other Notes:</u> Primarily used to administer next series of questions. Applicable to persons with current job. Applicable to persons age 16 or older.</p>
114	<p><u>Brief Description:</u> Hours worked</p> <p><u>Analytic Purpose:</u> Level of participation in employment activities; also used with 115 to, measure earnings and/or wage rate</p> <p><u>Other Notes:</u> Asked for main and second job. Applicable to persons age 16 or older. Applicable to persons with current job.</p> <p><u>Source:</u> Based upon SIPP</p>
115	<p><u>Brief Description:</u> Wage Rate and Pay Periods</p> <p><u>Analytic Purpose:</u> Used to measure earnings.</p> <p><u>Other Notes:</u> Asked for main and second job. Applicable to persons age 16 or older. Applicable to persons with current job.</p> <p><u>Source:</u> Based upon SIPP</p>

MODULE I: EMPLOYMENT/EDUCATION/OTHER DAY **ACTIVITY** (continued)

- 116 Brief Description: Job Activities
- Analvtic Purnose: Indicates occupation, frequently associated with such aspects of job as skill requirements, fringe benefits, job security, and promotion opportunities.
- Other Notes: Asked for main and second job.
 Applicable to persons age 16 or older.
 Applicable to persons with current job.
- 117 Brief Description: Whether job is part of sheltered workshop, enclave, or other DD program
- Analvtic Pumose: Indicates type of training and support services provided to persons with DD.
- Other Notes: Screening question; persons employed through such programs would be eligible for **followup** survey.
 Applicable to persons age 16 or older.
 Applicable to persons with current job.
- Source: Adapted from the Structural Training and Employment Transitional Services Demonstration Program
- 118 Brief Descrintion: Whether job is part of training program
- Analvtic Purnose: Indicates type of training and support services provided to persons with DD.
- Other Notes: Applicable to persons age 16 or older.
 Applicable to persons with current job.
- Source: Adapted from the Structural Training and Employment Transitional Services Demonstration Program
- I19-I20 Brief Description: Whether there is job coach
- Analvtic Puroose: Indicates type of training and support services provided to persons with DD.
- Other Notes: Applicable to persons age 16 or older.
 Applicable to persons with current job.
- Source: Adapted from the Structural Training and Employment Transitional Services Demonstration Program

MODULE I: EMPLOYMENT/EDUCATION/OTHER DAY **ACTIVITY** (continued)

- I21 **Brief Description:** Mode of and problems with transportation to job
- Analytic Purpose:** Indicates use of formal and informal source of transportation assistance and transportation barriers.
- Other Notes:** Applicable to persons age 16 or older.
 Applicable to persons with current job.
- Source:** Adapted from the Structural Training and Employment Transitional Services Demonstration Program
-
- I22-26 **Brief Description:** Assistance from others in choosing current job
- Analytic Purpose:** Used to indicate level of functioning in area of self-direction; also indicates type of support services used by persons with DD.
- Other Notes:** Applicable to persons age 16 or older.
 Applicable to persons with current job.
- Source:** Adapted from the National Consumer Survey
-
- I27 **Brief Description:** Whether on waiting list for employment services
- Analytic Purpose:** Indicates unmet demand for sheltered or supported employment services.
- Other Notes:** Applicable to persons age 16 or older.
-
- I28 **Brief Description:** Ever participated in DD Job Program
- Analytic Purpose:** Primarily used for screening purposes.
- Other Notes:** Screening question; persons previously participating in sheltered or supported employment program would be eligible for **followup** survey.
 Applicable to persons age 16 or older.

MODULE I: EMPLOYMENT/EDUCATION/OTHER DAY **ACTIVITY** (continued)

- I32a** Brief Description: Current school enrollment
- Other Notes: Primarily used to administer next series of questions.
-
- I32b** Brief Description: Previous receipt of special education services
- Analytic Purpose: Primarily used for screening purposes.
- Other Notes: Coded inapplicable if never attended school. Screening questions; persons previously receiving special education services would be eligible for **followup** survey. Applicable to persons age 16 or older.
-
- I34** Brief Description: Current receipt of special education services
- Analytic Purpose: Indicates type of formal services used by persons with DD.
- Other Notes: Screening question; persons currently receiving special education services would be eligible for **followup** survey. Applicable to persons currently enrolled in school.
-
- I35** Brief Description: Type of school: public/private, day/residential
- Analytic Purpose: Describes type of provider of special education services.
- Other Notes: Applicable to persons currently enrolled in school.

MODULE I: **EMPLOYMENT/EDUCATION/OTHER** DAY ACTIVITY (continued)

- 136 **Brief Description:** Out-of-pocket expenses for education
- Analytic Purpose:** Used to compute total private expenditures for persons with DD.
- Other Notes:** Applicable to persons currently enrolled in school.
-
- I37 **Brief Description:** Hours per week in school
- Analytic Purpose:** Used to indicate amount of educational services received.
- Other Notes:** Applicable to persons currently enrolled in school.
-
- I39 **Brief Description:** Whether receiving vocational training as part of school
- Analytic Purpose:** Used to indicate type of vocational services.
- Other Notes:** Applicable to persons currently enrolled in school.
 Applicable to persons age 16 or older.
- Source:** Adapted from the Structural Training and Employment Transitional Services Demonstration Program.
-
- I40-41 **Brief Description:** Participation in other job-related program
- Analytic Purpose:** Used to indicate type of vocational services.
- Other Notes:** Applicable to persons 18 or older.
- Source:** Adapted from the Structural Training and Employment Transitional Services Demonstration Program.

MODULE I: **EMPLOYMENT/EDUCATION/OTHER DAY ACTMTY** (continued)

- I43 Brief Description: Participation in other educational services
- Analytic Purpose: Used to describe other- activities related to acquisition of training or academic skills.
- Other Notes: Applicable to persons 18 or older.
- Source: Adapted from the Structural Training and Employment Transitional Services Demonstration Program.
-
- 145-147 Brief Description: Participation in adult day program
- Analytic Purpose: Indicates type and amount of other adult day services used by persons with DD.
- Other Notes: Applicable only to persons not currently attending school, working, or in a job-related training program.
 Applicable to persons 18 or older.
-
- 148 Brief Description: Mode of and problems with transportation to adult day program
- Analytic Purpose: Indicates use of formal and informal source of transportation assistance and transportation barriers.
- Other Notes: Applicable only to persons not currently attending school, working, or in a job-related training program.
 Applicable to persons 18 or older.

MODULE I: EMPLOYMENT/EDUCATION/OTHER DAY ACTIVITY (continued)

- 149 **Brief Description:** Provision of adult day activity as part of living arrangement
- Analytic Purpose:** Used to describe residential setting and services.
- Other Notes:** Applicable only to persons not currently attending school, working, or in a job-related training program.
 Applicable to persons 18 or older.
-
- I50-I51 **Brief Description:** Reimbursement sources and out-of-pocket expenses for adult day activity
- Analytic Purpose:** Used to calculate public and private costs for services to persons with DD.
- Other Notes:** Applicable to persons 18 or older.
-
- 152 **Brief Description:** Waiting list for adult day program
- Analytic Purpose:** Used to assess unmet demand for adult day programs.
- Other Notes:** Applicable to persons 18 or older.

MODULE J: CATEGORICAL CONDITIONS

This section obtains information on medical and other categorical conditions often associated with substantial functional limitations. Certain conditions with an onset prior to age 22 will be used as screening criteria for determining eligibility for **followup** survey.

- J1** Brief Description: Ever diagnosed with or had conditions
- Analytic Purpose: Used to describe range of conditions associated with functional limitations and developmental disabilities; also used to create subgroups for analysis.
- Other Notes: Screening question; persons with certain conditions (dependent upon age of diagnosis or first appearance of symptoms) would be eligible for **followup** survey.
-
- J2** Brief Description: Age when first diagnosed or had symptoms of each condition ,
- Analytic Purpose: Used to determine whether condition had an onset in the developmental period, a prerequisite for **defining** developmental disabilities.
- Other Notes: Age of onset is not asked for conditions known to occur or be present at birth. Screening question; persons with certain conditions (dependent upon age of diagnosis or first appearance of symptoms) would be eligible for **followup** survey.

MODULE K: HEALTH STATUS

This section obtains information on general physical health, including subjective assessment, health conditions and habits, and illness. This information would be used to describe health status and health care needs.

- K1** **Brief Description:** Subjective overall health status
- Analytic Purpose:** Obtains individual's (or proxy's) assessment of overall health. Permits comparison with national status.
- Source:** NHIS Core Question.
-
- K2** **Brief Description:** Days in bed due to **illness** or injury
- Analytic Purpose:** Bed days is a standard measure of health status and illness and can be compared with national statistics.
- Other Notes:** Reference period = past 12 months
- Source:** NHIS Core Question.
-
- K3-K4** **Brief Description:** Height and weight
- Analytic Purpose:** Permit assessment of weight problems and comparison with national norms.
- Source:** **NHIS** Core Question.

MODULE **K**: HEALTH STATUS (continued)

- K5** **Brief Description:** Current cigarette smoking behavior
- Analytic Purpose:** Identifies persons who may be at additional health risk due to smoking.
- Source:** Census Disability Add-on.
-
- K6** **Brief Description:** Other health conditions
- Analytic Purpose:** Identifies other significant health conditions or problems that may affect individual's functioning, service needs, and overall quality of life.
- Other Notes:** Reference periods = currently and ever

MODULE L: MEDICAL AND HEALTH SERVICES

L1a-e	<u>Brief Description:</u>	Doctor and other medical care provider visits
	<u>Analytic Purpose:</u>	Describes use of health care services by persons with DD.
	<u>Other Notes:</u>	Reference period = past 12 months
	<u>Source:</u>	NHIS Core Question.
L1f-h	<u>Brief Description:</u>	Reimbursement sources and out-of-pocket expenses for doctor visits
	<u>Analytic Purpose:</u>	Used to calculate public and private costs for services to persons with DD.
	<u>Other Notes:</u>	Reference period = past 12 months.
L1i-j	<u>Brief Description:</u>	Usual location of and mode of transportation to doctor visits
	<u>Analytic Purpose:</u>	Used to describe use of transportation services and transportation barriers to access to care.
L2a-b	<u>Brief Description:</u>	Overnight hospital stays
	<u>Analytic Purpose:</u>	Describes use of health care services by persons with DD.
	<u>Other Notes:</u>	Reference period = past 12 months.
	<u>Source:</u>	NHIS Core Question.

MODULE L: MEDICAL AND HEALTH SERVICES (continued)

L2c-e	<u>Brief Description:</u>	Reimbursement sources and out-of-pocket expenses for hospital stays
	<u>Analytic Purpose:</u>	Used to calculate public and private costs for services to persons with DD.
	<u>Other Notes:</u>	Reference period = past 12 months.
L3a-b	<u>Brief Description:</u>	Mental health hospital stays
	<u>Analytic Purpose:</u>	Describe use of health care services by persons with DD.
	<u>Other Notes:</u>	Reference period = past 12 months
L3c-e	<u>Brief Description:</u>	Reimbursement sources and out-of-pocket expenses for mental health hospital stays
	<u>Analytic Purpose:</u>	Used to calculate public and private costs for services to persons with DD.
	<u>Other Notes:</u>	Reference period = past 12 months.
L4a-b	<u>Brief Description:</u>	Nursing home stays
	<u>Analytic Purpose:</u>	Describes use of health care services by persons with DD.
	<u>Other Notes:</u>	Reference period = past 12 months.

MODULE L: MEDICAL AND HEALTH SERVICES (continued)

L4c-e Brief Description: Reimbursement sources and out-of-pocket expenses for nursing home stays

Analytic Purpose: Used to calculate public and private costs for services to persons with DD.

Other Notes: Reference period = past 12 months.

L5a Brief Description: Dentist visits

Analytic Purpose: Describes use of health care services by persons with DD.

Other Notes: Reference period = past 12 months.

L5b-d Brief Description: Reimbursement sources and out-of-pocket expenses for dentist visits

Analytic Purpose: Used to calculate public and private costs for services to persons with DD.

Other Notes: Reference period = past 12 months.

MODULE **M**: MENTAL HEALTH SERVICES

This section obtains information on the receipt and amount of psychological and behavior management services and on payment sources and out-of-pocket expenses for these services. This information will provide one component of total service utilization and expenditures. Note: hospitalization for mental health reasons is addressed in Module L.

- M1** **Brief Description:** Contact with mental health professionals
- Analytic Purpose:** Used to describe receipt/amount of psychological services, and determines current involvement in **MR/DD** system.
- Other Notes:** Reference period = past month
-
- M3** **Brief Description:** Current use of early intervention services
- Analytic Purpose:** Used to describe receipt/amount of early intervention services, and determines current involvement in **MR/DD** system.
- Other Notes:** Applicable to persons birth through **5** years.
 Reference period = past month.
 Screening question; persons receiving early intervention services would be eligible for **followup** survey.
-
- M5** **Brief Description:** Previous use of early intervention services
- Analytic Purpose:** Used to describe receipt/amount of early intervention services, and determines current involvement in **MR/DD** system.
- Other Notes:** Applicable to persons age 6 or older.
 Asked about receipt of services when individual was younger than 5 years. Screening question; persons receiving early intervention services would be eligible for **followup** survey.

MODULE **M**: MENTAL HEALTH SERVICES (continued)

- M6 Brief Description: Counseling on work or family problems or with social interactions in general
- Analytic Purpose: Used to describe receipt/amount of behavior management services, and determines current involvement in **MR/DD** system.
- Other Notes: Reference period = past month.
-
- M7 Brief Description: Reimbursement sources and out-of-pocket expenses for mental health services
- Analytic Purpose: Used to construct estimate of total public and private costs for services utilized by persons with DD.

MODULE N: CASE MANAGEMENT SERVICES

This section determines whether the individual has a case manager or receives case management services and whether these services are provided by a single agency for persons with **MR/DD**. This information will be used to describe total system of services and current involvement with **MR/DD** service system.

- N1** Brief Description: Receipt of case management services
- Analytic Purpose: Determines whether there is a case manager or someone providing some case management services.
- Other Notes: Reference period = past 6 months
 Screening question; persons receiving case management services from an **MR/DD** agency would be eligible for **followup** survey.
- Source: Based upon the University of Minnesota RRTC instrument.
-
- N2a** Brief Description: Frequency of contact with case manager(s)
- Analytic Purpose: Used to describe amount of case management services.
- Other Notes: Reference period = past 6 months.
-
- N2b-d** Brief Description: Source of case management services
- Analytic Purpose: Used to describe whether a single agency provides case management and whether any **MR/DD** agency is involved in providing such services.
- Other Notes: Screening question; persons receiving case management services from an **MR/DD** agency would be eligible for **followup** survey.
-

MODULE N: CASE MANAGEMENT SERVICES (continued)

N3

Brief Description: Receipt of case management services in past

Analytic Purpose: Used for screening purposes and to describe links with DD service system.

Other Notes: Reference period = past 5 years
Applicable to persons not currently receiving case management services.
Screening question; persons receiving case management **servies** **from** an **MR/DD** agency would be eligible for **followup** survey.

MODULE 0: FORMAL IN-HOME SUPPORT

This section provides information on the amount and type of formal services provided by visiting providers (that is, paid or volunteer staff who do not live at the individual's residence). This series is asked only of persons not living in group residences; see Section U for questions specific to group residences.

- 01 Brief Description: Number of formal providers
- Analytic Purpose: Used to help guide the respondent through the grid and to assess breadth of formal service network.
- Other Notes: Not asked of persons living in group residences.
- Source: Adapted from the National Long Term Care Demonstration.
-
- 02 Brief Description: Employer
- Analytic Purpose: Used to determine whether an agency is involved in arranging (and potentially paying) for services.
- Other Notes: Not asked of persons living in group residences.
- Source: Adapted from the National Long Term Care Demonstration.
-
- 03 Brief Description: Types of assistance provided
- Analytic Purpose: Used to describe type of formal services received.
- Other Notes: Not asked of persons living in group residences.
- Source: Adapted from the National Long Term Care Demonstration.

MODULE 0: FORMAL IN-HOME SUPPORT (continued)

04

Brief Description: Amount of assistance

Analytic Purpose: Used to determine total amount of formal services received.

Other Notes: Not asked of persons living in group residences.

Source: Adapted from the National Long Term Care Demonstration.

05-06

Brief Description: Reimbursement sources and out-of-pocket expenses

Analytic Purpose: Used to construct measure of public and private costs for services utilized by persons with DD.

Other Notes: Not asked of persons living in group residences.

MODULE **P**: FORMAL LIVE-IN SUPPORT

This section provides information on the amount and type of formal services provided by live-in paid or volunteer staff. **This** series is asked only of persons not living in group residences; see Section U for questions specific to group residences.

- P1** Brief Description: Number of formal providers
- Analytic Purpose: Used to help guide the respondent through the grid and to assess breadth of formal service network.
- Other Notes: Not asked of persons living in group residences.
- Source: Adapted from the National Long Term Care Demonstration.
-
- P2** Brief Description: Employer
- Analytic Purpose: Used to determine whether an agency is involved in arranging. (and potentially paying) for services.
- Other Notes: Not asked of persons living in group residences.
- Source: Adapted from the National Long Term Care Demonstration.
-
- P3** Brief Description: Types of assistance provided
- Analytic Purpose: Used to describe type of formal services received.
- Other Notes: Not asked of persons living in group residences.
- Source: Adapted from the National Long Term Care Demonstration.

MODULE P: FORMAL **LIVE-IN** SUPPORT (continued)

P4	<u>Brief Description:</u>	Amount of assistance
	<u>Analytic Purpose:</u>	Used to determine total amount of formal services received.
	<u>Other Notes:</u>	Not asked of persons living in group residences.
	<u>Source:</u>	Adapted from the National Long Term Care Demonstration.
P5-P6	<u>Brief Description:</u>	Reimbursement sources and out-of-pocket expenses
	<u>Analytic Purpose:</u>	Used to construct measure of public and private costs for services utilized by persons with DD.
	<u>Other Notes:</u>	Not asked of persons living in group residences.

MODULE Q: INFORMAL SUPPORT

This section obtains information on the sources, types, and amounts of informal care or **support** received by the individual. It also identifies the members of the informal **support** network by gender, relationship, and living arrangements and together with the formal services providers, both visiting and live-in, describes the total set of support services received by the individual. This section is applicable to all individuals regardless of whether or not they live in group residential facilities. If the individual lives with a relative who provides care or support, the amount of respite care provided in the last 6 months is obtained.

Q1 Brief Description: Number of caregivers

Analytic Purpose: Identifies size and composition of informal support network.

Other Notes: Applicable to all individuals, regardless of whether in group residential facility.

Source: Adapted from the National Long Term Care Demonstration.

Q2 Brief Description: Relationship of sample member

Analytic Purpose: Describes providers of informal support.

Other Notes: Applicable to all individuals, regardless of whether in group residential facility.

Source: Adapted from the National Long Term Care Demonstration.

Q3 Brief Description: Gender

Analytic Purpose: Describes providers of informal support.

Other Notes: Applicable to all individuals, regardless of whether in **group** residential facility.

MODULE Q: INFORMAL SUPPORT (continued)

- Q4 **Brief Description:** Living arrangements vis-a-vis sample member
- Analytic Purpose:** Describes providers of informal support and to identify informal supportive living arrangements.
- Other Notes:** Applicable to all individuals, regardless of whether in group residential facility.
-
- Q5 **Brief Description:** Types of assistance provided
- Analytic Purpose:** Identifies services provided informally.
- Other Notes:** Applicable to all individuals, regardless of whether in group residential facility.
- source:** Adapted **from** the National Long Term Care Demonstration.
-
- Q6-Q7 **Brief Description:** Amount of assistance provided
- Analytic Purpose:** Determines total amount of support services by all providers, formal or informal.
- Other Notes:** Applicable to all individuals, regardless of whether in group residential facility.
- Source:** Adapted from the National Long Term Care Demonstration.
-
- Q9 **Brief Description:** Whether financial assistance provided
- Analytic Purpose:** Identifies informal sources of financial supports.
- Other Notes:** Asked only of persons age 18 or older.
 Applicable to all individuals, regardless of whether in group residential facility.

MODULE Q: INFORMAL SUPPORT (continued)

- Q10** Brief Description: Amount of financial assistance provided
- Analytic Purpose: Determines total amount of financial support.
- Other Notes: Applicable to all individuals, regardless of whether in group residential facility.
-
- Q12** Brief Description: Provision of formal respite care
- Analytic Purpose: Determines whether live-in informal caregivers received respite from formal providers.
- Other Notes: Reference period = past 6 months
 Asked only of persons receiving any informal care from relatives living with them.
- Source: Medicare Alzheimer's Disease Demonstration and Research Project.
-
- Q13-Q14** Brief Description: Frequency/Amount of formal respite care
- Analytic Purpose: Describes amount of formally provided respite care.
- Other Notes: Reference period = past 6 months
 Asked only of persons receiving any informal care from relatives living with them.
- Source: Medicare Alzheimer's Disease Demonstration and Research Project.
-
- Q15** Brief Description: Location of formal respite care
- Analytic Purpose: Describes whether respite care provided in the individual's home, in a foster home, or in a center or facility.
- Other Notes: Asked only of persons receiving any informal care from relatives living with them.
- Source: Medicare Alzheimer's Disease Demonstration and Research Project.

MODULE R: **SOCIAL** INTERACTION/BEHAVIOR

This section obtains information on the social interaction patterns of persons age 5 or older, including the number of visits per week (by telephone or in-person) with friends or family who do not live with the individual and the proportion of friends who have disabilities, the frequency of participation in social events or visits to various community facilities, whether staff took part in these events or visits, and whether any of the other participants were persons with disabilities. Information is also obtained on transportation mode and problems, and on the individual's participation in decisions about leisure time activities.

These data can be used to measure the extent of social and community contact by persons in various living arrangements, the degree of supervision and/or independence provided for persons with DD in their leisure time activities, and transportation barriers or problems that may exist. This section also asked for reports of incidence and frequency of socially maladaptive behavior during the past month, for persons age 18 or older. (Data on behavior problems for younger persons is obtained in Section S.)

R2-R3 **Brief Description:** Frequency of calls or visits with family and friends

Analytic Purpose: Describes degree of social contact.

Other Notes: Asked of persons age 5 or older.
Reference period = past week

R5 **Brief Description:** Location of and transportation to visits

Analytic Purpose: Describes use of transportation services and transportation barriers for social activities.

Other Notes: Asked of persons age 5 or older.
Applicable to visits in another person's residence and in public places.

MODULE **R**: SOCIAL INTERACTION/BEHAVIOR (continued)

- R7 **Brief Description:** Number of friends, with and without disabilities
- Analytic Purpose:** Describes total size of friendship network and degree to which the network provides social interaction with nondisabled persons.
- Other Notes:** Asked of persons age 5 or older.
-
- R8a **Brief Description:** Participation in social events/contact with community facilities
- Analytic Purpose:** Describes degree of social contact and participation in community events.
- Other Notes:** Reference period = past month
 Asked of persons age **5** or older.
-
- R8b **Brief Description:** Participation as part of group and/or with friends with and without disabilities
- Analytic Purpose:** Describes degree of supervision provided for leisure activities and opportunities for social interaction with nondisabled persons.
- Other Notes:** Asked of persons age **5** or older.
-
- R10 **Brief Description:** Transportation to **events**
- Analytic Purpose:** Describes use of transportation services and transportation barriers for social activities.
- Other Notes:** Asked of persons age 5 or older.

MODULE **R**: SOCIAL INTERACTION/BEHAVIOR (continued)

- R11** Brief Description: Participation in decisions regarding leisure activities
- Analytic Purpose: Measures one aspect of self-direction.
- Other Notes: Asked of persons age 5 or older.
 Screening question; persons for whom someone else chooses
 leisure activities, dependent upon age (for example, age 16 or
 older), would be eligible for **followup** survey.
- Source: Adapted from the National Consumer Survey.
-
- R13-R14** Brief Description: Incidence and frequency of socially maladaptive behaviors
- Analytic Purpose: Describes behaviors **that may** indicate emotional disturbance and
 behavior problems as a secondary disability for persons with
 DD; these problems may pose significant barriers to more
 independent employment and living arrangements and require
 closer supervision of the individual's activities.
- Other Notes: Applicable to persons age 18 or older; related questions for
 younger persons are in Module S.
 Reference period = past month
- Source: Adapted from the Temple Behavior Development Survey.

MODULE S • CHILD MODULE: DEVELOPMENTAL MILESTONES AND BEHAVIOR

This section obtains information on the physical, cognitive, and social development of children up to age 17. Questions **S1** through **S50** provide data on the development/functioning level of young children through age 4, including evidence of behavior problems. Questions **S51** through **S82** obtain information on behavior problems for older children age 5 through 17; information on functioning in the seven life areas is obtained, as appropriate for children of various ages, in earlier modules.

S1-S50	<u>Brief Description:</u> Social/Cognitive/Development (young children age 0-4)
	<u>Analytic Purpose:</u> Used to describe functioning (achievement of age appropriate developmental milestones) for young children.
	<u>Other Notes:</u> Applicable to persons age 4 or younger.
	<u>Source:</u> Adapted from the 1981 Child Health Supplement to the NHIS.
S50a-j	<u>Brief Description:</u> Behavior Problems (age 0-4)
	<u>Analytic Purpose:</u> Used to describe maladaptive behavior for young children.
	<u>Other Notes:</u> Applicable to persons age 4 or younger.
	<u>Source:</u> Adapted from Health and Developmental Status section of 1990 Longitudinal Followup to the National Maternal and Infant Health Survey.
S51-S82	<u>Brief Description:</u> Behavior Problems (age 4-17)
	<u>Analytic Purpose:</u> Used to describe maladaptive behavior for older children.
	<u>Other Notes:</u> Applicable to persons age 4 through 17.
	<u>Source:</u> Adapted from the 1981 Child Health Supplement to the NHIS.

MODULE T: INCOME SUPPORT

This section obtains information on receipt of income support through various public programs, including SSI, other Social Security benefits, Medicare, Medicaid, Food Stamps, and General Public Assistance. It also contains screening questions for the purposes of identifying persons who would be administered the full set of questions in a **followup** survey.

T1	<u>Brief Description:</u> Receipt of Supplemental Security Income
	<u>Analytic Purpose:</u> Used to construct measures of public expenditures for persons with DD.
	<u>Source:</u> Adapted from SIPP.
T2	<u>Brief Description:</u> Receipt of Social Security Payments
	<u>Analytic Purpose:</u> Used to construct measures of public expenditures for persons with DD.
	<u>Source:</u> Adapted from SIPP .
T1b,T2b	<u>Brief Description:</u> Representative Payee
	<u>Analytic Purpose:</u> Determines degree of independent functioning in handling of money.
	<u>Other Notes:</u> Screening question; persons who have a representative payee would be eligible for the followup survey.

MODULE **T**: INCOME SUPPORT (continued)

T2c-g	<p><u>Brief Description:</u> Reason for receiving Social Security</p> <p><u>Analytic Purpose:</u> Used to construct measures of public expenditures for persons with DD.</p> <p><u>Other Notes:</u> Screening questions; persons receiving Social Security payments because of a disability acquired before age 22 would be eligible for the followup survey.</p> <p><u>Source:</u> Adapted from SIPP.</p>
T3	<p><u>Brief Description:</u> Medicare Status</p> <p><u>Analytic Purpose:</u> Used to construct measures of public support and access to medical services.</p> <p><u>Source:</u> Adapted from SIPP.</p>
T4	<p><u>Brief Description:</u> Medicaid Status</p> <p><u>Analytic Purpose:</u> Used to construct measures of public support and access to medical services.</p> <p><u>Source:</u> Adapted from SIPP.</p>
T5	<p><u>Brief Description:</u> Receipt of Food Stamps</p> <p><u>Analytic Purpose:</u> Used to construct measures of public expenditures for persons with DD.</p> <p><u>Other Notes:</u> If the individual is younger than 18, their inclusion in households receiving assistance is obtained.</p>

MODULE T: INCOME SUPPORT (continued)

T6	<p><u>Brief Description:</u> Receipt of Other Public Assistance</p> <p><u>Analytic Purpose:</u> Used to construct measures of public expenditures for persons with DD.</p> <p><u>Other Notes:</u> If the individual is younger than 18, their inclusion in households receiving assistance is obtained.</p> <p><u>Source:</u> Adapted from SIPP.</p>
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MODULE U • FACILITIES MODULE: FORMAL STAFF SUPPORT

This section obtains information in the services available to residents of group facilities, as well as on the level of licensing or certification held by the facilities.

- U1** Brief Description: Ownership Status
- Analytic Purpose: Used to describe the administrative arrangements of group facilities.
- Source: Adapted from the **NMES** Institutional Population Component.
-
- u 2** Brief Description: Number of Beds
- Analytic Purpose: Used as measure of size
- Source: Adapted from the NMES Institutional Population Component.
-
- u 3** Brief Description: Primary Handicapping Conditions Served
- Analytic Purpose: Used to characterize facility.
- Source: Adapted from the **NMES** Institutional Population Component.
-
- U3a** Brief Description: Type of Group Facility
- Analytic Purpose: Used to characterize facility.
- Source: Adapted from the NMES Institutional Population Component.

MODULE U - FACILITIES MODULE: FORMAL STAFF SUPPORT (continued)

U4-U5	<u>Brief Description:</u>	Types of services provided to residents
	<u>Analvtic Purpose:</u>	Used to characterize level of care provided at facility and whether the facility provides the total environment for residents.
	<u>Source:</u>	Adapted from the NMES Institutional Population Component.
U6-U9	<u>Brief Description:</u>	Licensure/Accreditation
	<u>Analvtic Purpose:</u>	Used to characterize facility.
	<u>Source:</u>	Adapted from the NMES Institutional Population Component.
U10-U17	<u>Brief Description:</u>	Number of Beds Certified Under Medicare and Medicaid as ICF-MR, ICF, SNF
	<u>Analvtic Purpose:</u>	Describes level of care provided to residents and indicates cost of care.
	<u>Source:</u>	Adapted from the NMES Institutional Population Component.
U18,U23	<u>Brief Description:</u>	Types of Contracted/Employed Staff
	<u>Analvtic Purpose:</u>	Indicates types of staff available to provide services and can be used to compute staff to resident ratios.
	<u>Source:</u>	Adapted from the NMES Institutional Population Component.

MODULE U - FACILITIES MODULE: FORMAL STAFF SUPPORT (continued)

- U19-U22 Brief Description: Waiting Liits
- Analytic Purpose: Used to estimate unmet demand for residential services.
- Source: Adapted from the NMES Institutional Population Component.
-
- U24 Brief Description: Hours of Volunteer Time
- Analytic Purpose: Used to indicate ratio of total staff time (paid and volunteer) to residents.
- Source: Adapted from the NMES Institutional Population Component.

MODULE V: INTERVIEWER OBSERVATIONS

This section obtains information on the housing structure based on interviewer observations, and on the use of proxy respondents during the interview.

- V1-v3 Brief Description: Type and Size of Housing Structure
Analytic Purpose: Used to describe physical characteristics of living arrangements.
- v 4 Brief Description: Health and Safety Problems Observed at Residence
Analytic Purpose: Used to describe physical characteristics of living arrangements.
- V5 Brief Description: Distinctive Appearance of Exterior of Residence
Analytic Purpose: Used to describe physical characteristics of living arrangements.
Source: Adapted from the University of Minnesota RRTC instrument.
- V6 Brief Description: Other Types of Structures in Neighborhood
Analytic Purpose: Used to describe physical characteristics of neighborhood.
Source: Adapted from the University of Minnesota RRTC instrument.

MODULE **V**: INTERVIEWER OBSERVATIONS (continued)

V7-V9 Brief Description: Role of Proxy Respondent

Analytic Purpose: Used to evaluate quality of responses and to indicate level of independence in dealing with strangers.

PART III: PROTOTYPE INSTRUMENT

CONTENTS

MODULE

- A. **LIVING** ARRANGEMENTS/DEMOGRAPHICS
- B. RECEPTIVE/EXPRESSIVE **COMMUNICATION**
- C. LEARNING
- D. MOBILITY
- E. SELF-CARE
- F. INDEPENDENT **LIVING**
- G. SELF-DIRECTION
- H. EQUIPMENT/DEVICES
- I. EMPLOYMENT/EDUCATION/OTHER DAY **ACTIVITY**
- J. CATEGORICAL CONDITIONS
- K. **HEALTH** STATUS
- L. MEDICAL AND **HEALTH** SERVICES
- M. MENTAL HEALTH SERVICES
- N. CASE MANAGEMENT SERVICES
- O. **FORMAL SUPPORT**
- P. LIVE-IN FORMAL SUPPORT
- Q. **INFORMAL** SUPPORT
- R. SOCIAL **INTERACTION/BEHAVIOR**
- S. CHILD MODULE DEVELOPMENTAL MILESTONES AND BEHAVIOR
- T. INCOME SUPPORT
- U. FACILITIES MODULE: FORMAL STAFF SUPPORT
- V. **INTERVIEWER OBSERVATIONS**

A. LIVING ARRANGEMENTS/DEMOGRAPHICS

LIVING ARRANGEMENTS

- (C) A1. a. What are the names of all persons living or staying here? Start with the name of the person or one of the persons who owns or rents this place (REFERENCE PERSON).
- b. What is your (PERSON'S) relationship to (REFERENCE PERSON)?
- c. Do all of the persons you have named usually live here?
- d. How old are you (is PERSON)?
- e. What is your (PERSON'S) exact date of birth?
- f. Is (PERSON) male or female? (ASK ONLY IF APPROPRIATE)

(a) Name	(b) Relationship (SEE CODES BELOW)	(c) Usually Lives Here	(d) Age	(e) Date of Birth	(f) Sex
1. _____	REFERENCE PERSON	Yes = 01 No = 00 DK = -1	_____ YEARS DK	____/____/____ DK = -1	M = 01 F = 02
2. _____		Yes = 01 No = 00 DK = -1	_____ YEARS DK	____/____/____ DK = -1	M = 01 F = 02
3. _____		Yes = 01 No = 00 DK = -1	_____ YEARS DK	____/____/____ DK = -1	M = 01 F = 02
4. _____		Yes = 01 No = 00 DK = -1	_____ YEARS DK	____/____/____ DK = -1	M = 01 F = 02
5. _____		Yes = 01 No = 00 DK = -1	_____ YEARS DK	____/____/____ DK = -1	M = 01 F = 02

RELATIONSHIP CODES:

PARENT (BIOLOGICAL/ADOPTED)	.01
FOSTER PARENT	.02
SPOUSE	.03
SIBLING	.04
CHILD	.05
FOSTER CHILD	.06
OTHER RELATIVE	.07
NON-RELATIVE (LANDLORD/LADY)	.08
NON-RELATIVE CAREGIVER/PAID STAFF	.09
NON-RELATIVE (FRIEND/ROOMMATE)	.10

NOTE: THE NHIS OBTAINS INFORMATION ON GENDER THROUGH INTERVIEWER OBSERVATION.

A2. **INTERVIEWER:** IS PERSON LIVING WITH A PARENT (01), FOSTER PARENT (02). SPOUSE (03), CHILD OR FOSTER CHILD (05,06), AND/OR **OTHER RELATIVE (07)?**

YES01 (SKIP TO Q.A10)

NO.00

(S) A3. Are there any persons who are paid to live here as staff?

*YES01 (ADD NAMES AND RELATIONSHIP CODES
TO HOUSEHOLD GRID IN Q.A1)

NO.00

DON'T KNOW.-1

A4. Are there any persons who live here and rent rooms to other people as roomers or boarders, or who get reimbursed for letting others live here?

YES01 (ADD NAMES AND RELATIONSHIP CODES
TO HOUSEHOLD GRID IN Q.A1)

NO.00

DON'T KNOW. -1

A5. a. Is this place a...

CIRCLE ONE

*supervised apartment01
*group home02
*halfway house.03
*personal care or boarding home04
*developmental center05
*some other type of supervised group
 residence or facility.06
NONE OF THE ABOVE.00 (SKIP TO Q.A6.b)
DON'T **KNOW** -1 (SKIP TO Q.A6.b)

b. How long have you (has PERSON) been living here?

|____|____| YEARS

DON'T **KNOW** -1 => (ASK IF AGE 50 OR OLDER:)
Did you (PERSON) move here
before or after you (he/she)
was **50**?

*BEFORE AGE 50.01

AFTER AGE 5002

DON'T **KNOW** -1

- c. Who paid or is expected to pay for your (PERSON'S) living arrangements for the past 12 months?

CIRCLE ALL THAT APPLY

You (PERSON) and/or your (his/her) family ..01
Medicare or Medicare HMO.02
Medicaid.03
Veteran's benefits,04
Private insurance or non-Medicare HMO . . .05
OTHER (SPECIFY)06

No cost to you (PERSON,) and/or your
(his/her) family or to third party
payor07
Included as part of residential services. ..08
DON'T KNOW.-1

d. INTERVIEWER: WILL ANY OF THE COSTS FOR (THIS/THESE)
LIVING **ARRANGEMENT(S)** BE PAID BY PERSON
AND/OR HIS/HER FAMILY?

YES.01
NO00 (SKIP TO Q.A6.a)
DON'T KNOW-1 (**SKIP** TO Q.A6.a)

- e. In total, in the past 12 months, how much did you (PERSON) and/or your (his/her) family have to pay for (this/these) living arrangement(s), excluding costs that will be paid back by insurance?

\$ |__|__|__|__|__|
DON'T KNOW.-1

A6. a. **INTERVIEWER:** IS THIS A GROUP **RESIDENCE?** (CODES 02-05 IN **Q.A5**)

YES. **.01** (SKIP TO Q.A10)

NO **.00**

b. Is your (PERSON'S) house/apartment/room...

STOP AT FIRST
"YES"

owned by you (PERSON) or someone
in your (his/her) family with a
mortgage or loan. **.01**

owned by you (PERSON) or someone
in your (his/her) family free
and clear (without a mortgage). . . . **.02** (SKIP TO **Q.A9.a**)

rented for cash rent, **.03** (SKIP TO **Q.A8.a**)

occupied without payment of cash
rent, or. **.04** (SKIP TO **Q.A9.a**)

provided to you (PERSON) or paid
for by an agency? **.05** (SKIP TO **Q.A10**)

DON'T KNOW. **.-1** (SKIP TO **Q.A10**)

A7. a. What is your (PERSON'S) monthly mortgage?

\$ |__|__|__|__|

DON'T KNOW. **.-1**

b. Does your (PERSON'S) mortgage payment include insurance and/or taxes?

YES **.01** (SKIP TO **Q.A9.a**)

NO. **.00** (SKIP TO **Q.A9.a**)

DON'T KNOW. **.-1** (SKIP TO **Q.A9.a**)

AS. a. What is your (PERSON'S) monthly rent?

\$ |__|__|__|__|

DON'T KNOW. -1

b. Does your (PERSON'S) rent include meals and/or utilities?

YES 0 1

NO 0 0

DON'T KNOW. -1

A9. a. (In addition to your (PERSON'S) monthly rent or mortgage,) do you (does PERSON) pay any housing fees on a regular basis (such as a maintenance or association fee)?

YES 0 1

NO. -.00 (SKIP TO Q.A10)

DON'T KNOW. -1 (SKIP TO Q.A10)

b. What does this fee cover?

(Write In)

c. (In total) how much is this fee?

\$ |__|__|__|__|

PER WEEK.01

PER MONTH.02

PER YEAR.0 3

OTHER (SPECIFY)04

DON'T KNOW. -1

A10. a. INTERVIEWER: IS PERSON AGE 18 OR OLDER?

YES. **.01**

NO **.00 (SKIP TO Q.A11)**

b. Did you (PERSON) choose the place where you (he/she) currently live(s) by yourself (him/herself), did you (he/she) make the decision with others, or did someone make the decision for you (him/her)?

CIRCLE ONE

DECISION MADE BY SELF **.01**

DECISION MADE WITH OTHERS **.02 (SKIP TO Q.A10.e)**

DECISION MADE BY SOMEONE ELSE **.03 (SKIP TO Q.A10.f)**

DON'T **KNOW..** **.1**

c. Did you (PERSON) talk about your (his/her) choices with anybody before you (he/she) made the decision?

YES **.01**

NO. **.00 (SKIP TO Q.A11)**

DON'T **KNOW.** **.-1 (SKIP TO Q.A11)**

d. Did the person who you (PERSON) talked to the most...

CIRCLE ALL THAT APPLY

give you (him/her) advice on
how to choose or find a
place to live, or **.01**

actually help you (him/her) find
a place to live (e.g., look
through ads, go with you
(him/her) to look at places). **.02**

DON'T KNOW. **.-1**

e. Who else was involved in making this decision?

CIRCLE ALL THAT APPLY

A personal friend01 (SKIP TO Q.All)
A family member02 (SKIP TO Q.All)
Your (his/her) legal guardian03 (SKIP TO Q.All)
A staff member from an agency,
like a case manager or school
counselor04 (SKIP TO Q.All)
OTHER (SPECIFY)05 (SKIP TO Q.All)

DON'T KNOW.-1 (SKIP TO Q.All)

f. Who made this decision for you (PERSON)? Was he or she...

CIRCLE ONE

A personal friend01
A family member02
Your (his/her) legal guardian03
A staff member from an agency
or a school counselor04
OTHER (SPECIFY)05

DON'T KNOW-1

- (C) **A12.** a. What is the highest grade or year of school you have (PERSON has) ever attended, (including the grade or year you (he/she) may be in now)?

ELEMENTARY SCHOOL: 12 3 4 5 6 7 8

HIGH SCHOOL: 9 10 11 12

COLLEGE: 12 3 4 5 **6+**

NEVER ATTENDED SCHOOL **.01**

DON'T KNOW. -1

NOTE: THE NHIS **ASKS** ABOUT HIGHEST GRADE OR **YEAR** FOR **REGULAR** SCHOOL ONLY.

- b. **INTERVIEWER:** IS PERSON AGE 16 OR OLDER?

YES. **.01**

NO **.00 (SKIP TO Q.A13)**

- c. Do you now have...

CIRCLE ONE

a regular high school diploma **.01**

a special high school diploma **.02**

a certificate of attendance or
completion. **.03**

a GED certificate, or **.04**

have you (has PERSON) not completed
high school?. **.05**

DON'T KNOW. -1

(C) A13. a. What is the number of the group or groups which represents your (PERSON'S) race?

CIRCLE ALL THAT APPLY

Aleut, Eskimo, or American Indian01
Asian or Pacific Islander02
Black.....03
White.....04
Another group not listed (SPECIFY). ..05

DON'T KNOW.....-1 (SKIP TO Q.A14)

IF MULTIPLE ENTRIES, ASK Q.A13.b

b. Which of those groups; that is, (entries in 3a) would **you say** BEST represents your (PERSON'S) race?

CIRCLE ONE

Aleut, Eskimo, or American Indian ...01
Asian or Pacific Islander02
Black..03
White.....04
Another group not listed (SPECIFY). ..05

DON'T KNOW.....-1

(C) A14. a. Are any of those groups your (PERSON'S) national origin or ancestry? (Where did your (PERSON'S) ancestors come from?)
READ LIST FROM Q.A14.b.

YES... .01

NO. . . .00 (SKIP TO Q.A15)

DON'T KNOW. . . .-1 (SKIP TO Q.A15)

NOTE: THE RESPONDENT IS GIVEN A CARD IN THE NHIS.

b. Please give me the number of the group.

CIRCLE ONE

Puerto Rican. . . .01

Cuban02

Mexican/Mexicano. . . .03

Mexican American. . . .04

Chicano05

Other Latin American. . . .06

Other Spanish07

(C) A15. Are you (Is PERSON) now married, widowed, divorced, separated, or have you (has PERSON) never been married?

CIRCLE ONE

Married-spouse in household01
Married-spouse not in household02
Widowed03
Divorced.04
Separated05
Never married06
DON'T KNOW.-1

NOTE: THE NHIS INTERVIEWER CODES **WHETHER** SPOUSE IS **IN** THE HOUSEHOLD **IF MARRIED AND IDENTIFIES WHICH OTHER** HOUSEHOLD **MEMBER** IS THE SPOUSE. THE **INTERVIEWER** IS ALSO **ASKED** TO MARK A BOX IF THE SAMPLE **MEMBER** IS **UNDER** AGE 14.

A16. a. INTERVIEWER: IS PERSON LIVING IN A SUPERVISED GROUP RESIDENCE?

YES. **.01** (SKIP TO NEXT MODULE)

NO **.00**

(C)

b. Was the total combined FAMILY income during the past 12 months more or less than **\$20,000**? Include money from jobs, Social Security, retirement income, unemployment payments, public assistance, and so forth. Also include income from interest, dividends, net income from business, farm, or rent, and any other money received. (FAMILY INCOME IS THE TOTAL COMBINED INCOME OF ALL THE PEOPLE WHO LIVE HERE WHO ARE RELATED TO EACH OTHER.)

LESS THAN \$20,000 **.01**

\$20,000 OR MORE **.02**

DON'T KNOW. -1 (SKIP TO NEXT MODULE)

R E F U S E D -3 (SKIP TO NEXT MODULE)

NOTE: IN **THE NHIS** THE RESPONDENT IS HANDED ONE OF Two CARDS, **DEPENDING UPON WHETHER FAMILY** INCOME IS-LESS THAN \$20,000 OR MORE THAN \$20,000.

- c. Of those income groups, which letter best represents the total combined FAMILY income during the past 12 months? Include wages, salaries, and other items we-just talked about.

NOTE: RESPONSE CATEGORIES ON **THE** CARD IN THE NHIS **ARE** LISTED AS A-ZZ.

CIRCLE ONE

<u>Less than \$20,000</u>	OR	<u>\$20,000 or more</u>
Less than \$ 1,000. .. .01		\$20,000 - \$24,999. . . .01
\$ 1,000 - \$ 1,999. .. .02		\$25,000 - \$29,999. . . .02
\$ 2,000 - \$ 2,999. .. .03		\$30,000~ \$34,999. . . .03
\$ 3,000 - \$ 3,999. .. .04		\$35,000 - \$39,999. . . .04
\$ 4,000 - \$ 4,999. .. .05		\$40,000 - \$44,999. . . .05
\$ 5,000 - \$ 5,999. .. .06		\$45,000 - \$49,999. . . .06
\$ 6,000 - \$ 6,999. .. .07		\$50,000 and over07
\$ 7,000 - \$ 7,999. .. .08		DON'T KNOW-1
\$ 8,000 - \$ 8,999. . . .09		REFUSED.-3
\$ 9,000 - \$ 9,999. . . .10		
\$10,000 - \$10,999. .. .11		
\$11,000 - \$11,999. .. .12		
\$12,000 - \$12,999. .. .13		
\$13,000 - \$13,999. .. .14		
\$14,000 - \$14,999. .. .15		
\$15,000 - \$15,999. .. .16		
\$16,000 - \$16,999. .. .17		
\$17,000 - \$17,999. .. .18		
\$18,000 - \$18,999. .. .19		
\$19,000 - \$19,999. .. .20		
DON'T KNOW-1		
REFUSED. :..... .-3		

NOTE: C = NHIS Core Questionnaire item.

B. RECEPTIVE/EXPRESSIVE COMMUNICATION

INTERVIEWER: IS THIS INTERVIEW BEING CONDUCTED WITH A PROXY
WITHOUT THE SAMPLE PERSON PRESENT?

YES01 (ADMINISTER THIS MODULE TO PROXY)

NO.00 (COMPLETE THIS MODULE AFTER
THE INTERVIEW BY INTERVIEWER
OBSERVATION)

B1. How does (PERSON) usually communicate? Is it by using...

CIRCLE ONE

Speech (words, sentences, etc.)01

Writing or typing02

Sign language/finger spelling03

Communication device (SPECIFY).04

Other non-verbal gestures/
vocalizations05

Some other way (SPECIFY).06

Does not communicate thoughts or
needs to others07 (SKIP TO Q.B3)

DON'T KNOW.-1 (SKIP TO Q.B3)

(S) B2. How well would you say (PERSON) communicates (his/her) needs to other people?

STOP AT
FIRST "YES"

Can be understood completely and
easily by both strangers and
those who know (him/her) well.01

*Can be understood only by those
who know (him/her) well.02

*Can be understood partially and/or
with difficulty by strangers03

*Little can be understood either
by those who know (him/her)
well or strangers04

*Does not attempt to communicate
needs05

DON'T KNOW.-1

(S) B3. How well would you say (PERSON) communicates (his/her) thoughts or ideas to other people?

STOP AT
FIRST "YES"

Can be understood completely and
easily by both strangers and
those who know (him/her) well.01

*Can be understood only by those
who know (him/her) well.02

*Can be understood partially and/or
with difficulty by strangers03

*Little can be understood either
by those who know (him/her)
well or strangers04

*Does not attempt to communicate
thoughts or ideas05

DON'T KNOW.-1

B4. In what way must people usually communicate with (PERSON) in order for them to be understood?

CIRCLE ONE

Speech (words, sentences, etc.)01

Writing or typing 02

Sign language/finger spelling 03

Communication device (SPECIFY). 04

Other non-verbal gestures/
vocalizations 05

Some other way (SPECIFY). 06

NO COMMUNICATION POSSIBLE 00 (SKIP TO NEXT MODULE)

DON'T KNOW. -1 (SKIP TO NEXT MODULE)

(S) B5. How well would you say (PERSON) understands other people when they talk or ask questions?

STOP AT
FIRST "YES"

Understands completely and easily
both strangers and those who know
(him/her) well01

*Understands strangers only partially
and/or with difficulty02

*Understands only those (he/she)
knows well03

*Understands little by those (he/she)
knows well or strangers.04

*Does not or cannot listen
or attend to speech.05

DON'T KNOW-1

NOTES: (S) ■ SCREENING QUESTION; * ■ RESPONSE CATEGORIES USED
TO IDENTIFY **PERSONS** FOR **FOLLOWUP SURVEY**.

C. LEARNING

Cl. a. **INTERVIEWER:** IS **PERSON** AGE 5 OR **OLDER?**

YES01

NO.00 (SKIP TO NEXT MODULE)

b. Are you (Is PERSON) able to...

STOP AT
FIRST "YES"

write or type complete letters to
people you (he/she) know(s) or
write out complete lists like a
grocery list?01

write or type short sentences?.02

write, print, or type some words
without copying or tracing?.....03

trace or copy your (his/her) own
name or some other words, or.04

are you (is PERSON) not able to write,
print, trace, or copy words?.05

DON'T KNOW.-1

C2. Are you (Is PERSON) able to...

STOP AT
FIRST "YES"

read newspapers and magazines or
most books.01
(REGULAR OR LARGE PRINT OR BRAILLE)

read books like those for young adults
(REGULAR OR LARGE PRINT OR BRAILLE) . .02

read simple stories like picture books
or comics (REGULAR OR LARGE PRINT OR
BRAILLE).03

read street signs like "STOP" or
"WALK" or signs for the women's
room or men's room, or.04

recognize 10 words or more.05

do you (does PERSON) recognize no
words or signs?06

DON'T KNOW.-1

c3. Are you (Is PERSON) able to...

STOP AT
FIRST "YES"

do addition and subtraction like
5+6 and 10-5?01

count how many items you (he/she)
have (has), like toys or items
in your (his/her) shopping cart,
up to 10 items?02

count out loud from 1 to 10?03

count up to 2 items like blocks or
things in a shopping cart?.04

understand the difference between
having one item and having many
items, or05

do you (does PERSON) have no
understanding of numbers or
amounts of things?.06

DON'T KNOW.-1

c4. **INTERVIEWER:** IS PERSON AGE 5-17 YEARS?

YES.01

NO00 (SKIP TO **NEXT** MODULE)

(S) (C) C5. Does any impairment or health problem NOW keep you (PERSON) from attending school? (THIS INCLUDES BOTH SPECIAL AND REGULAR SCHOOLS. IF PERSON RECEIVES HOMEBOUND EDUCATION/TUTORING, CODE "YES".)

* Y E S 0 1
NO00 (SKIP TO Q.C6)
DON'T KNOW -1

C5a. Are you (Is PERSON) receiving homebound education or tutoring?

YES01 (SKIP TO NEXT MODULE)
NO00 (SKIP TO NEXT MODULE)
DON'T KNOW. -1 (SKIP TO NEXT MODULE)

(S) (C) C6. Do you (Does PERSON) attend a special school or special classes because of any impairment or health problem?

*YES.01 (SKIP TO Q.C8)
NO 0 0
DON'T KNOW -1

(S) (C) C7. Do you (Does PERSON) need to attend a special school or special classes because of any impairment or health problem?

* Y E S 0 1
NO 0 0
DON'T KNOW -1

(S) (C) C8. Are you (Is PERSON) limited in school attendance because of your (his/her) health?

*YES.01

NO.00

DON'T KNOW..-1

C9. a. INTERVIEWER: IS **PERSON PREVENTED FROM OR LIMITED** IN SCHOOL ATTENDANCE, OR **ATTENDS/NEEDS** SPECIAL SCHOOL OR CLASSES?

YES01

NO.00 (SKIP TO NEXT MODULE)

b. What condition causes this?

(Write In)

IF INJURY/OPERATION: When did [the (INJURY) occur?/(PERSON) have the operation?]

IF OPERATION OVER 3 MONTHS AGO: For what condition did you (PERSON) have the operation?

IF OPERATION 0-3 MONTHS OR IF PREGNANCY **REASK** SAYING: Except for (CONDITION)...?

c. Besides (CONDITION) is there any other condition that causes this limitation?

YES.01 (REASK Q.C9.a)

NO00 (SKIP TO Q.C9.d)

DON'T KNOW -1 (SKIP TO Q.C9.d)

d. Is this limitation caused by any (other) specific condition?

*YES.01 (REASK Q.C9.a)

NO00

DON'T KNOW1

e. Which of these conditions would you say is the main cause of this limitation?

CONDITION: _____
(Write In)

f. How old were you when you first had this condition? (CODE "00" IF AT BIRTH)

|____|____| AGE

DON'T KNOW -1 => Was it before or
after you turned
221

NOTES: (S) = SCREENING QUESTION: * = RESPONSE CATEGORIES USED
TO IDENTIFY PERSONS FOR FOLLOWUP SURVEY.

NOTE: C = NHIS Core Questionnaire item.

D1. INTERVIEWER: IS PERSON AGE 5 YEARS OR OLDER?	
YES01
NO.00 (SKIP TO Q.D9)

NO.00 (SKIP TO Q.D9)

CIRCLE ONE

DON'T KNOW -1

CIRCLE ONE

DON'T KNOW -1

D4. Taking into account any special equipment you have (he/she has) or any help you (he/she) receive(s), how well do you (does PERSON) get around in your (his/her) own (HOME/ROOM/APARTMENT)? Do you (Does PERSON) do that...

CIRCLE ONE

Without difficulty,.01

With difficulty, or.02

Are you (Is PERSON) not able to do that? .00

DON'T KNOW-1

(S) D5. How well do you (does PERSON) move up and down a flight of stairs without help of another person or special equipment? Do you (Does PERSON) do that...

CIRCLE ONE

Without difficulty,.01 (SKIP TO Q.D7)

*With difficulty, or.02 (SKIP to Q.D7)

*Are you (Is PERSON) not able to do that? .00

DON'T KNOW-1

D6. Taking into account any special equipment you have (he/she has) or any help you (he/she) receive(s), how well do you (does PERSON) able to move up and down a flight of stairs? Do you (Does PERSON) do that...

CIRCLE ONE

Without difficulty,.01

With difficulty, or.02

Are you (Is PERSON) not able to do that? .00

DON'T KNOW-1

DRAFT - MODD

MRDD-D.QUE (QUE)

D.2

2/26/90

(S) D7. How well do you (does PERSON) get around outside the (HOME/ROOM/APARTMENT) without help of another person or special equipment?
Do you (Does PERSON) do that...

(INTERVIEWEE: THIS INCLUDES SAFETY AND THE ABILITY TO **NOT** GET LOST.)

CIRCLE ONE

Without difficulty,01 (SKIP TO Q.D9)

*With difficulty, or.02 (SKIP TO Q.D9)

*Are you (Is PERSON) not able to do that? . .00

DON'T KNOW-1

D8. Taking into account any special equipment you have (he/she has) or any help you (he/she) receive(s), how well do you (does PERSON) get around your (his/her) neighborhood? Do you (Does PERSON) do that...

CIRCLE ONE

Without difficulty,01

With difficulty, or.02

Are you (Is PERSON) not able to do that? . .00

DON'T KNOW-1

D9. **INTERVIEWER: IS PERSON AGE 16 OR OLDER?**

YES.01

NO00 (SKIP TO NEXT MODULE)

D10. Do you (Does PERSON) have a license or permit to drive a car?

YES0 1

NO00 (SKIP TO Q.D12)

DON'T KNOW-1 (SKIP TO Q.D12)

DRAFT - MODD

MRDD-D.QUE (QUE)

D.3

2/26/90

D11. In order for you (PERSON) to be able to drive a car, are special equipment or modifications to the car necessary?

YES (SPECIFY).01

NO00

DON'T KNOW-1

D12. Which of the following types of public transportation have you (has PERSON) used in the past month?

CIRCLE ALL THAT APPLY

Bus 0 1

Train.02

Subway.03

Taxicab.04

Van or other special transportation
service.05

NONE OF THE ABOVE.06 (SKIP TO NEXT MODULE)

DON'T KNOW-1 (SKIP TO NEXT MODULE)

D13. Do you (Does PERSON) usually use public transportation without any kind of help or supervision **or does** someone usually provide assistance such as arranging for the services, accompanying you (him/her), or helping you (him/her) in or out of the vehicle?

USES SERVICES WITHOUT HELP OR
SUPERVISION.01

REQUIRES ASSISTANCE OF ANOTHER
PERSON.02

DON'T KNOW-1

NOTES: (S) - **SCREENING** QUESTION; * - RESPONSE **CATEGORIES USED**
TO IDENTIFY PERSONS FOR **FOLLOWUP** SURVEY.

E. SELF-CARE

El. a. INTERVIEWER: IS PERSON AGE 5 YEARS OR OLDER?

YES. 01

NO 00 (SKIP TO NEXT MODULE)

(S) El. The next questions are about day to day activities. When answering these questions, please think about the past week.

For each activity I mention, tell me how you do (PERSON does) these activities: without help or supervision, with supervision or reminders to perform them safely and appropriately, or with help from **someone to actually do the activity**. I'd also like you to tell me what, if any, special equipment you use (PERSON uses).

The first activity is eating. During the past week, what, if any, special equipment did you (PERSON) use for (INSERT ACTIVITY)?

During the past week, did you (PERSON) eat by yourself (him/herself) (using only equipment you just mentioned), did someone remind or watch you (PERSON) to make sure you (he/she) ate appropriately, or did someone help you (PERSON) eat or actually feed you (him/her)?
(REPEAT QUESTIONS FOR EACH ACTIVITY BELOW.

	SPECIAL EQUIPMENT (WRITE-IN)	* PERSON NEEDS SOMEONE TO		* PERSON NEEDS HELP FROM		NOT APPLICABLE	OK
		PERSON DOES BY SELF	REMIN/ SUPERVISE	HELP FROM SOMEONE			
a. EATING (INCLUDING CUTTING FOODS, BUTTERING BREAD, GETTING FOOD FROM PLATE TO MOUTH, CHEWING/SWALLOWING, MANAGING FEEDING TUBE).	_____	01	02	03	04	-1	
b. GETTING IN OR OUT OF A BED OR CHAIR.	_____	01	02	03	04	-1	
c. DRESSING (GETTING CLOTHES APPROPRIATE FOR THE TIME OF DAY AND SEASON AND PUTTING THEM ON).	_____	01	02	03	04	-1	
d. BATHING OR SHOWERING (INCLUDING TURNING THE WATER ON AND OFF AND WASHING THOROUGHLY).	_____	01	02	03	04	-1	

(S) E2. If you need (PERSON needs) to take prescription medication--that is, medication a doctor prescribes for you (him/her) that must be obtained at a pharmacy (or clinic in a residential setting), does somebody usually remind you (him/her) to take the medication or measure out the correct amount?

*YES, SOMEONE REMINDS AND/OR MEASURES01
N O 0 0
DON'T KNOW -1

E3. How do you (does PERSON) usually take care of urinary needs?

CIRCLE ONE

Do you use (Does he/she use) a
catheter (internal or external)?01
Do you use (Does **he/she** use)
a bedpan?02
Do you use (Does **he/she** use)
absorbent pads/diapers?03
Do you use (Does **he/she** use)
a standard or modified toilet?04
DON'T **KNOW** -1

E4. How do you (does PERSON) usually take care of bowel needs?

CIRCLE ONE

Do you use (Does he/she use)
a colostomy bag?01
Do you use (Does he/she use)
a bedpan?02
Do you use (Does he/she use)
absorbent pads/diapers?03
Do you use (Does he/she use)
a standard or modified toilet?04
DON'T **KNOW** -1

(S) E5. a. INTERVIEWER: DOES PERSON USE BEDPAN OR DIAPERS ONLY?

*YES.01 (SKIP TO Q.E6)

NO00

b. INTERVIEWER: DOES PERSON USE TOILET?

YES.01

NO00 (SKIP TO Q.E5.c)

(S) c. During the past week, did you (PERSON) take care of your toileting needs you yourself, did someone usually remind you to use the toilet on time or watch to see if you (PERSON) needed help, or did someone help you (PERSON) get to the toilet on time or clean yourself (him/herself) afterwards?

BY SELF.01

*SOMEONE REMINDS/WATCHES.02

*SOMEONE HELPS.03

DON'T KNOW-1

d. INTERVIEWER: DOES PERSON USE CATHETER OR COLOSTOMY BAG?

YES.01

NO00 (SKIP TO Q.E6)

(S) e. During the past week, did you (PERSON) take care of the (catheter/colostomy bag) yourself (himself/herself), did someone usually remind you, or did someone help you take care of (it/them) or do it for you?

BY SELF.01

*SOMEONE REMINDS., . . .02

*SOMEONE HELPS.03

DON'T KNOW-1

E6. How many times do you (does PERSON) have urinary accidents--that is, you (he/she) wet(s) your (his/her) clothing or bedding? Do you...

CIRCLE ONE

never or very rarely have
urinary accidents?01

have urinary accidents once
or twice a week?02

have urinary accidents three
or more times a week?.03

NOT TOILET TRAINED00

DON'T KNOW-1

E7. How many times do you (does PERSON) have bowel accidents--that is, you (he/she) soil(s) your (his/her) clothing or bedding? Do you...

CIRCLE ONE

never or very rarely have
bowel accidents?01

have bowel accidents once or
twice a week?.. .. .02

have bowel accidents three or
more times a week?03

NOT TOILET TRAINED00

DON'T KNOW-1

NOTES: (S) ■ SCREENING QUESTION: * ■ RESPONSE CATEGORIES USED TO IDENTIFY PERSONS FOR **FOLLOWUP** SURVEY, DEPENDENT **UPON** AGE (FOR **EXAMPLE**, ASSISTANCE IN TARING PRESCRIPTION MEDICATION **WOULD** NOT **DETERMINE** ELIGIBILITY FOR SURVEY IF PERSON WAS AGE 12 OR YOUNGER, AND MOST OTHER CRITERIA WOULD NOT APPLY FOR PERSONS YOUNGER **THAN** 3).

F. INDEPENDENT LIVING

F1. INTERVIEWER: IS PERSON AGE 12 YEARS OR OLDER?

YES01

NO.00 (SKIP TO Q.F6)

(S) F2. Next, I have some questions about activities around the house.
Again, think about last week.

For each task I mention, please tell me how you (PERSON) perform(s) these activities: without help or supervision, with supervision or reminders to perform them safely and appropriately, or with help from someone to actually do the activity. I'd also like you to tell me what special equipment you use (PERSON uses).

During the past week, what, if any, special equipment did you (PERSON) use for (INSERT ACTIVITY).

During the past week, did you (PERSON) prepare full meals by yourself (him/herself), (using any equipment you just mentioned), did someone remind or watch you (PERSON) to make sure you (he/she) prepared the food appropriately and safely, or did someone help you (him/her) or actually prepare the food for you (him/her)?

(REPEAT QUESTIONS FOR EACH ACTIVITY BELOW.)

	SPECIAL EQUIPMENT (WRITE-IN)	PERSON NOT APPLICABLE					OK
		PERSON DDES BY SELF	PERSON NEEDS OR REMINDING	NEEDS (DONE AS PART PHYSICAL OF RESIDENTIAL HELP	S E R V I	OTHER/NOT APPEL CABLE	
a. PREPARING FULL MEALS (SUCH AS MEAT AND A VEGETABLE, EITHER FRESH OR FROZEN FOODS/DINNERS)	_____	01	02	03	04	05	-1
b. PREPARING LIGHT MEALS OR SNACKS (SUCH AS SANDWICHES, SOUPS, GETTING COOKIES/CHIPS MILK/JUICE).	_____	01	02	03	04	05	-1
c. DOING LIGHT HOUSEHOLD CHORES (SUCH AS WASHING DISHES, TIDYING-UP, DUSTING)	_____	01	02	03	04	05	-1
d. GROCERY SHOPPING (DECIDING WHAT TO BUY, PAYING FOR ITEMS)	_____	01	02	03	04	05	-1
e. DOING LAUNDRY (LOADING/ OPERATING MACHINES, USING APPROPRIATE AMOUNT OF DETERGENT)	_____	01	02	03	04	05	-1

F3. Do you (Does PERSON) use regular telephone equipment?

Y E S 0 1

N O 0 0

DON'T **KNOW** -1

(S) F4. When you need (PERSON needs) to find a telephone number, do you (does PERSON) look the number up yourself (him/herself) in the telephone book or does someone else help you (him/her)?

CIRCLE ONE

LOOKS UP BY SELF01

*SOMEONE ELSE HELPS02

DON'T **KNOW** -1

F5. When you need (PERSON needs) to use the telephone, do you (does he/she) usually dial the number yourself (him/herself) or does someone help you (him/her)?

CIRCLE ONE

DIALS BY SELF.01

SOMEONE ELSE HELPS/DIALS02

DON'T KNOW -1

NOTES: (8) = **SCREENING** QUESTION; * = RESPONSE CATEGORIES USED TO IDENTIFY PERSONS FOR **FOLLOWUP** SURVEY.

<p>F6. a. INTERVIEWER: DOES PERSON REQUIRE ASSISTANCE WITH ANY MOBILITY, SELF-CARE, OR INDEPENDENT LIVING ACTIVITIES (REVIEW MODULES D, E, AND F)?</p> <p>YES01</p> <p>NO.00 (SKIP TO NEXT MODULE)</p>

(S) (C) b. What condition causes this?

(Write In)

IF INJURY/OPERATION: When did [the (INJURY) occur?/(PERSON) have the operation?]

IF OPERATION OVER 3 MONTHS AGO: For what condition did you (PERSON) have the operation?

IF OPERATION 0-3 MONTHS OR IF PREGNANCY REASK SAYING: Except for (CONDITION)...?

c. Besides (CONDITION) is there any other condition that causes this limitation?

YES.01	(RE-ASK	Q.F6.b	THEN
				GO TO	Q.F6.d)
NO00	(SKIP TO	Q.F6.e)	
DON'T KNOW-1	(SKIP TO	Q.F6.e)	

- d. Which of these conditions would you say is the main cause of this limitation?

CONDITION: _____
(Write In)

- e. How old were you when you first had this condition? (CODE "00" IF AT BIRTH)

____|____|

DON'T KNOW-1 => Was it before or
after you turned
221

*BEFORE 22. . .01

AFTER 22 .. .02

DON'T KNOW ..-1

G. SELF-DIRECTION

G1. INTERVIEWER: IS **PERSON** AGE 18 OR **OLDER**?

YES.01

NO00 (SKIP TO NEXT MODULE)

(S) G2. Do you (Does PERSON) have a legal, court-appointed guardian?

*YES..0 1

NO 0 0

DON'T KNOW -1

(S) G3. Do you (Does PERSON) give your (his/her) own consent for medical care, or does someone else do that for you (him/her)?

RESPONDENT GIVES CONSENT01 (SKIP TO Q.G5)

*SOMEONE ELSE GIVES CONSENT02

DON'T KNOW-1 (SKIP TO Q.G5)

G4. Who generally gives medical consent for you (PERSON)?

CIRCLE ONE

Family member.01

Legal guardian02

Agency or school staff member.03

OTHER (SPECIFY).04

DON'T KNOW-1

I'd like to ask you a few questions about how you (PERSON) handle(s) your (his/her) money.

G5. Do you (Does PERSON) go shopping yourself (him/herself) to buy things like clothes and personal items?

Y E S 0 1
NO ,00 (SKIP TO Q.G8)
DON'T KNOW -1 (SKIP TO Q.G8)

(S) **G6.** When you go shopping, do you select your own items?

Y E S 0 1
* N O 0 0
DON'T KNOW -1

(S) **G7.** Do you (Does PERSON) usually pay the money to the salesperson yourself (him/herself) or does someone help you (him/her)?

BY SELF.01
*SOMEONE HELPS.02
DON'T KNOW -1

(S) **G8.** Do you (Does he/she) usually take care of your (his/her) bills by yourself (him/herself) or does someone help you (him/her) budget your (his/her) money and make sure your (his/her) bills get paid?

BY SELF.01
*SOMEONE HELPS.02
DOES NOT RECEIVE BILLS03
DON'T KNOW -1

G9. Do you (Does PERSON) have a bank account of your (his/her) own--like a savings account or checking account?

Y E S 0 1

NO00 (SKIP TO Q.G11)

DON'T **KNOW**-1 (SKIP TO Q.G11)

(S) **G10.** Do you (Does PERSON) usually put money into your (his/her) bank account and take it out by yourself (him/herself), or does someone help you (him/her) do that? (DO NOT **COUNT BANK** EMPLOYEES)

BY SELF.01

*SOMEONE HELPS.02

DON'T **KNOW**-1

(S) **G11.** Do you (Does PERSON) have to have another person co-sign checks that are made out to you?

* Y E S 0 1

NO00

DON'T **KNOW**-1

NOTES: **Measures** in eelf-direction are also found **in** the following **modules**:

Choosing Residence

(Living **Arrangements/Demographics**, Module A)

Choosing Employment

(Employment/Education/Other Day Activity, Module I)

Need for **Supervision**

(Modules **E** and **F** (Self-Care and Independent Living);
Modules O, P, and Q (Formal and Informal Support))

Choosing Leisure **Activities**

(Module **R**)

Need for **Representative** Payee

(Income Support, Module T)

NOTES: (S) = **SCREENING** QUESTION; * = **RESPONSE CATEGORIES** USED
TO IDENTIFY PERSONS FOR **FOLLOWUP** SURVEY.

H. EQUIPMENT/DEVICES

- (S) H1. Which of the following equipment or special aids do you (does PERSON) currently or regularly use? (READ ITEMS IN LISTS 1 AND 2, CODE WITHOUT ASKING ANY ITEMS/EQUIPMENT REPORTED IN PREVIOUS QUESTIONS.)

<u>LIST 1</u>	<u>YES</u>	<u>NO</u>	<u>DK</u>
*Manual or motorized wheelchair or scooter	01	00	-1
*Crutches or walker	01	00	-1
Leg, back, or other type of brace	01	00	-1
Artificial arm or leg	01	00	-1
*Assistive communication device (e.g., communication board)	01	00	-1
Specially trained animals (e.g., guide dog)	01	00	-1
*Respirator	01	00	-1
*Feeding tube or machine	01	00	-1
Specially equipped telephone (TTY, TTD, amplified)	01	00	-1
Any other equipment or aids (SPECIFY)	01	00	-1

<u>LIST 2</u>			
Special shoes	01	00	-1
Colostomy bag	01	00	-1
Urinary catheter	01	00	-1
Absorbent pads/diapers	01	00	-1
Clothing with special fasteners or snaps	01	00	-1
Special dishes, cups or utensils to assist in eating	01	00	-1
Braille or other adapted watch	01	00	-1
Any other equipment or special supplies (SPECIFY)	01	00	-1

NOTE: OVERLAPS WITH EQUIPMENT USED TO ASSIST IN FUNCTIONING. NEEDED TO LEAD INTO QUESTIONS ON COSTS OF EQUIPMENT.
--

H2. INTERVIEWER: IS "YES" CIRCLED FOR ANY EQUIPMENT/AIDS
IN Q.H1, LIST 1?

YES01

NO. . . ,00 (SKIP TO Q.H4)

(S) H3. a. How old were you (was PERSON) when you (he/she) first began using
(this/these) equipment or aid(s)?

|_|_| AGE IN YEARS

(RECORD 00 IF LESS THAN ONE YEAR OLD)

DON'T KNOW -1 => Was it before or
after you (he/she)
turned 22?

*BEFORE 22 . .01

AFTER 22. . .02

DON'T KNOW. .-1

b. Did you (PERSON) and/or your (his/her) family pay for all or part
of the cost of (READ ITEMS FROM LIST 1)?

Y E S0 1

NO00 (SKIP TO Q.H4)

DON'T KNOW-1 (SKIP TO Q.H4)

c. In total, how much did you (PERSON) and/or your (his/her) family
have to pay for this/these item(s), excluding costs that will be
paid back by insurance?

\$ |_|_|_|_|_|

DON'T KNOW-1

H4. INTERVIEWER: IS "YES" CIRCLED FOR ANY EQUIPMENT/AIDS
IN Q.H1, LIST 2?

YES01

NO.00 (SKIP TO Q.H6)

H5. a. Did you (PERSON) and/or your (his/her) family pay for all or part of the cost of (READ ITEMS FROM LIST 2)?

YES01

NO00 (SKIP TO Q.H6)

DON'T KNOW -1 (SKIP TO Q.H6)

b. In total, in the past 12 months, how much did you (PERSON) and/or your (his/her) family have to pay for this/these item(s), excluding costs that will be paid back by insurance?

\$ |__|__|__|__|__|

DON'T KNOW -1

H6. I am going to read you a list of physical or structural modifications that may be made in people's homes. Please tell me which of these modifications you need (PERSON needs) and which ones are in place where you live (PERSON lives).

	NEEDS	IN PLACE	PLACE, DOES NOT NEED	DON'T KNOW
Shower seat, tub stool, or bath chair.	01	02	03	-1
Hand held shower	01	02	03	-1
Raised toilet.	01	02	03	-1
Portable toilet.	01	02	03	-1
Widened doorway(s)	01	02	03	-1
Ramp(s)	01	02	03	-1
Removed door sills or raised threshold	01	02	03	-1
Moved light switches, electrical outlets, and/or heating and cooling controls	01	02	03	-1
Adjusted height of cabinets/storage areas, counter tops, sinks	01	02	03	-1
Changed or repositioned sink or shower controls. .	01	02	03	-1
Faucets on side or front of sinks.	01	02	03	-1
Lever-style door handles	01	02	03	-1
Visual signals for telephone or door	01	02	03	-1
Braille or raised markings	01	02	03	-1
Accessible parking space or garage	01	02	03	-1
Sidewalks with curb cuts	01	02	03	-1
OTHER (SPECIFY).	01	02	03	-1

NOTE: THIS INFORMATION WILL BE USED WITH
OTHER MODULES TO DESCRIBE RESIDENTIAL
ENVIRONMENT..

H7. **INTERVIEWER: ARE ANY PHYSICAL** OR STRUCTURAL
MODIFICATIONS 'IN PLACE' IN Q.H6?

YES01

NO.00 (SKIP TO NEXT MODULE)

H8. Was your (PERSON'S) residence chosen because of or remodeled to have these features or modifications?

CHOSEN FOR MODIFICATIONS01 (SKIP TO NEXT MODULE)

REMODELED TO HAVE MODIFICATIONS.02

DON'T KNOW.-1 (SKIP TO NEXT MODULE)

H9. a. Did you (PERSON) and/or your (his/her) family make or have someone else make these modifications to your (his/her) residence, or were they arranged for by an agency?

PERSON/FAMILY MADE OR ARRANGED
FOR MODIFICATIONS.01

AGENCY MADE OR ARRANGED FOR
MODIFICATIONS.00 (SKIP TO **NEXT** MODULE)

DON'T KNOW.-1 (SKIP TO NEXT MODULE)

b. Did you (PERSON) and/or your (his/her) family receive any financial assistance or reimbursement to help pay for these modifications?

Y E S 0 1

NO.00

DON'T KNOW-1

I. EMPLOYMENT/EDUCATION/OTHER DAY ACTIVITY

EMPLOYMENT

I1. INTERVIEWER: IS PERSON AGE 16 **YEARS** OR OLDER?

YES01 .

NO.00 (SKIP TO Q.I32)

- (C) 12. Do you (Does PERSON) have a steady source of income--that you get (he/she gets) every other week or so--that covers your (his/her) basic needs like housing, food, clothing, and transportation? Do you (Does PERSON)...

CIRCLE ONE

have a steady source of income that
covers basic needs?01

have a steady source of income but
it doesn't cover needs? or,.02

do you (does PERSON) not have
steady source of income?03

DON'T KNOW-1

13. Do you (Does PERSON) have enough money for fun activities and for "little extras" like home decorations or special personal items?

Y E S0 1

N O0 0

DON'T KNOW-1

(C) 14. What were you (was PERSON) doing most of the past 12 months; working at a job or business, keeping house, going to school, or something else? (PRIORITY, IF 2 OR MORE ACTIVITIES REPORTED: 1) SPENT THE MOST TIME DOING, 2) CONSIDERS THE MOST IMPORTANT).

WORKING.01

KEEPING HOUSE.02 (SKIP TO Q.I7.a)

GOING TO SCHOOL (INCLUDING TRAINING,
OR DAY HABILITATION PROGRAM)03 (SKIP TO Q.I8.a)

SOMETHING ELSE04 (SKIP TO Q.I8.a)

DON'T KNOW -1 (SKIP TO Q.I8.a)

(S) (C) I5. Does any impairment or health problem now keep you (PERSON) from working at a job or business?

*YES.01 (SKIP TO Q.I9)

NO 0 0

DON'T KNOW -1

(S) (C) I6. Are you (Is PERSON) limited in the kind or amount of work you (he/she) can do because of any impairment or health problem?

*YES.01 (SKIP TO Q.I9)

NO00 (SKIP TO Q.I10)

DON'T KNOW -1 (SKIP TO Q.I10)

(s) (C) 17. a. Does any impairment or health problem now keep you (PERSON) from doing any housework at all?

*YES01 (SKIP TO Q.I9)

NO00

DON'T KNOW-1

b. Are you (Is PERSON) limited in the kind or amount of housework you (he/she) can do because of any impairment or health problem?

*YES.01 (SKIP TO Q.I9)

N O00 (SKIP TO Q.I0)

DON'T KNOW-1 (SKIP TO Q.I0)

(S) (C) 18. a. Does any impairment or health problem keep you (PERSON) from working at a job or business?

*YES.01 (SKIP TO Q.I9)

N O00

DON'T KNOW-1

b. Are you (Is PERSON) limited in the kind or amount of work you (he/she) can do because of any impairment or health problem?

*YES.01 (SKIP TO Q.I9)

N O00 (SKIP TO Q.I10)

DON'T KNOW-1 (SKIP TO Q.I10)

(S) (C) I9. a. What condition causes this?

(Write-In)

IF INJURY/OPERATION: When did [the (INJURY) occur?/(PERSON) have the operation?]

IF OPERATION OVER 3 MONTHS AGO: For what condition did you (PERSON) have the operation?

IF OPERATION 0-3 MONTHS OR IF PREGNANCY RE-ASK SAYING: Except for (CONDITION)...?

b. Besides (CONDITION) is there any other condition that causes this limitation?

YES.01 (RE-ASK Q.I9.a THEN
GO TO Q.I9.c)

NO00 (SKIP TO Q.I9.d)

DON'T KNOW-1 (SKIP TO Q.I9.d)

c. Which of these conditions would you say is the main cause of this limitation?

CONDITION: _____
(Write-In)

d. How old were you when you (PERSON) first had this condition?
(CODE "00" IF AT BIRTH)

I - I - f AGE-IN YEARS

(RECORD "00" IF LESS THAN ONE YEAR OLD)

DON'T KNOW -1 => Was it before
or after you
(PERSON) turned
22?

*BEFORE 22 . . .01

AFTER 22 . . .02

DON'T KNOW . . -1

(C) 110. During the past 2 weeks, did you (PERSON) work at any time at a job
or business not counting work around the house? (Include unpaid work
in the family farm or business.)

YES.01 (SKIP TO Q.113)

N O 0 0

DON'T KNOW -1 (SKIP TO Q.127)

(C) 111. Were you (Was PERSON) looking for work or on lay-off from a job
during those 2 weeks?

CIRCLE ONE

LOOKING FOR WORK01 (SKIP TO Q.127)

ON LAY-OFF02 (SKIP TO Q.127)

NOT LOOKING FOR WORK OR ON LAY-OFF03

DON'T KNOW -1 (SKIP TO Q.127)

112. Why were you (was PERSON) not working or looking for a job?

CIRCLE ALL THAT APPLY

UNABLE FOR HEALTH REASONS.01 (SKIP TO Q.I27)

LACK OF JOB SKILLS02 (SKIP TO Q.I27)

DISCRIMINATION03 (SKIP TO Q.I27)

CANNOT FIND A JOB.04 (SKIP TO Q.I27)

CHOOSES NOT TO WORK.05 (SKIP TO Q.I27)

OTHER (SPECIFY).06 (SKIP TO Q.I27)

DON'T KNOW-1 (SKIP TO Q.I27)

113. a. During the past 2 weeks, did you (PERSON) have or work at more than one job?

Y E S 0 1

N O00 (SKIP TO Q.I14)

DON'T KNOW-1 (SKIP TO Q.I14)

b. How many jobs did you (PERSON) have or work at during the past 2 weeks?

|__|__| JOBS

DON'T KNOW-1

INTERVIEWER INSTRUCTION: IN QUESTIONS I14-I16, CODE THE JOB AT WHICH THE PERSON WORKED THE MOST HOURS AS HIS/HER MAIN JOB. IF PERSON HAS ONLY ONE JOB, CODE THIS AS THE MAIN JOB.
--

114. Last week, how many hours did you (PERSON) work (at each job)?

```

MAIN      JOB:_____ HOURS      JOB      2:  _____ HOURS

DON'T KNOW      .....  .-1      DON'T KNOW. .... .-1

```

115. How much do you (does PERSON) **get** paid for the work that you do (he/she does) (at each job)?

MAIN JOB: \$ __ __ __ __ __	JOB2: \$ __ __ __ __ __
PER HOUR.01	PER HOUR.01
PER DAY.02	PER DAY02
PERWEEE...03	PER WEEK.03
PER TWO WEEKS.04	PER TWO WEEKS04
TWICE A MONTH.05	TWICE A MONTH05
ONCE A MONTH06	ONCE A MONTH.06
OTHER (SPECIFY).07	OTHER (SPECIFY)07
<hr/>	
NOT PAID08	NOT PAID.08
DON'T KNOW-1	DON'T KNOW.-1

116. **a.** What kind of work do you (does PERSON) do?

MAIN JOB: _____

JOB 2: _____

(Write-In)

b. What are your (PERSON'S) most important activities?

MAIN JOB: _____

JOB 2: _____

(Write-In)

(S) 117. (Are any of/Is) **your** (PERSON'S) current job(s) in a sheltered workshop or enclave. or in an other program for persons with developmental disabilities?

*YES.01 (SKIP TO Q.I19)

N O 0 0

DON'T KNOW-1

(S) 118. a. Did you (PERSON) get or learn (any of) your (his/her) job(s) through a special training program?

Y E S 0 1

NO00 (SKIP TO Q.I19)

DON'T KNOW-1 (SKIP TO Q.I19)

b. Was the training program...

CIRCLE ONE

*A transitional or supported
employment program01

A vocational rehabilitation program, or. . .02

Another training program (SPECIFY)03

DON'T KNOW-1

(S) 119. Is there someone at work who helps you (PERSON) learn how to do your (his/her) job or someone that you (PERSON) can ask questions about how to do your (his/her) job?

*YES.01

N O00 (SKIP TO Q.I21)

DON'T KNOW -1 (SKIP TO Q.I21)

(S) 120. Is this person someone who works with you (PERSON), a supervisor at work, someone from a training program, or someone else?

CIRCLE ALL THAT APPLY

CO-WORKER.01

SUPERVISOR.02

*SOMEONE FROM A TRAINING PROGRAM
(JOB COACH).03

SOMEONE ELSE/OTHER (SPECIFY)04

DON'T KNOW -1

121. a. How did you (PERSON) get to your (his/her) job(s) during the past two weeks?

CIRCLE ALL THAT APPLY

DRIVEN BY **PARENTS/FRIENDS/HOUSEPARENTS** . . .01

PICKED UP IN VAN/CAR/SCHOOL BUS/
SPECIAL B U S 0 2

T A X I 0 3

PUBLIC BUS/OTHER PUBLIC TRANSPORTATION .. .04

WALK/BICYCLE05

DRIVE(S) SELF.06

WORK AT RESIDENCE, NO TRANSPORTATION
NEEDED07

OTHER (SPECIFY).08

DON'T **KNOW** -1

- b. Do you (Does PERSON) have any problems or concerns with transportation to and from work?

Y E S 0 1

NO00 (SKIP TO **Q.I22**)

DON'T KNOW -1 (SKIP TO **Q.I22**)

c. What problems or concerns do you (does PERSON) have?

PUBLIC TRANSPORTATION IS NOT AVAILABLE. . .01

PUBLIC TRANSPORTATION IS NOT ACCESSIBLE. . .02

SPECIAL TRANSPORTATION IS NOT AVAILABLE. . .03

NEEDS ASSISTANCE WITH TRAINING IN
ARRANGING OR USING TRANSPORTATION.04

TRANSPORTATION IS TOO COSTLY05

TRANSPORTATION IS INCONVENIENT06

TRANSPORTATION IS UNRELIABLE07

OTHER (SPECIFY).08

DON'T KNOW -1

122. Did you (PERSON) choose your (his/her) **current** job or did someone else make the choice for you (him/her)?

INDIVIDUAL MADE CHOICE01

SOMEONE ELSE MADE CHOICE02 (SKIP TO Q.I26)

DON'T KNOW . . . , -1 (SKIP TO Q.I27)

123. Did you (he/she) talk about your (his/her) choices with anybody before you (he/she) made the decision?

YES 0 1

NO00 (SKIP TO Q.I27)

DON'T KNOW -1 (SKIP TO Q.I27)

124. Did the person you (he/she) talked to help by...

giving advice, or.01

by actively looking for jobs for you
(him/her)?02

DON'T KNOW-1

125. Who helped you (him/her) make the decision?

CIRCLE ALL THAT APPLY

Personal friend (unpaid)01 (SKIP TO Q.I27)

Family member.02 (SKIP TO Q.I27)

Legal guardian03 (SKIP TO Q.I27)

Agency or school staff member.04 (SKIP TO Q.I27)

OTHER (SPECIFY).00 (SKIP TO Q.I27)

DON'T KNOW-1 (SKIP TO Q.I27)

126. Who made this decision for you (PERSON)?

CIRCLE ALL THAT APPLY

Personal friend (unpaid)01

Family member.02

Legal guardian03

Agency or school staff member.04

OTHER (SPECIFY).00

DON'T KNOW-1

127. Are you (Is PERSON) on a waiting list for...

	<u>YES</u>	<u>NO</u>	<u>DK</u>
a. A sheltered workshop program.01	00	-1
b. A transitional or supported employment program	01	00	-1
c. A vocational rehabilitation program01	00	-1
d. Another job training program.01	00	-1

(S) 128. Have you ever participated in a (another) sheltered workshop or job training program for persons with developmental disabilities?

*YES01	
NO	0	0
DON'T KNOW		-1

EDUCATION

NO QUESTIONS 129-131 IN THIS DRAFT.

132. a. Do you (Does PERSON) go to school now?
- YES.01 (SKIP TO Q.I34)
- NO0 0
- DON'T KNOW-1

(S) b. When you (PERSON) went to school, did you (he/she)'...

				NEVER	
				ATTENDED	DON'T
				S C H O	KNOWL
	<u>YES</u>	<u>NO</u>			
a.					
Attend special classes					
or a special school.	01	00	-4	-1	
b.					
Get special tutoring or					
instruction <u>outside</u> of					
your (his/her) usual					
classroom (e.g., in a					
resource room)	01	00	-4	-1	
c.					
Receive occupational or					
physical therapy or other					
related services during					
the usual school day	01	00	-4	-1	

* * * ALL SKIP TO Q.I40 * * *

THERE IS NO QUESTION 133 IN THIS DRAFT.

(S) 134. As part of school, do you (does PERSON)...

* DON'T
YES NO KNOW

- a. Get special tutoring or instruction outside of your (his/her) usual classroom (e.g., in a resource room) 01 00 -1
- b. Receive occupational or physical therapy or other related services during the usual school day. **.01** 00 -1

135. a. Is the school that you go (PERSON goes) to a public or private school?

CIRCLE ONE

PUBLIC **.01**

PRIVATE. **.02**

DON'T **KNOW** -1

b. Are **you** (Is PERSON) a day student or do you (does PERSON) live at school during the school year?

CIRCLE ONE

DAY STUDENT. **.01**

RESIDENTIAL STUDENT. **.02**

DON'T KNOW -1

136. a. Do you (Does PERSON) or your (his/her) family pay any school tuition or fees? (Including residential fees or room and board.)

YES..... .01

NO00 (SKIP TO Q.I37)

DON'T KNOW-1 (SKIP TO Q.I37)

b. In total, how much do you (does PERSON) or your (his/her) family have to pay for tuition or fees? (Including residential fees or room and board.)

\$ |__|__|__|__|

PER MONTH.01

PER SEMESTER0 2

PER SCHOOL YEAR.03

DON'T KNOW-1

137. How many hours per week do you (does PERSON) attend school?

|__|__| HOURS PER WEEK

DON'T KNOW -1

138. **INTERVIEWER:** IS PERSON AGE 16 OR OLDER?

YES.01

N O00 (SKIP TO NEXT MODULE)

139. a. As part of going to school, are you (is PERSON) currently learning about jobs and work?

YES.01

NO00 (SKIP TO Q.I40)

DON'T KNOW-1 (SKIP TO Q.I40)

b. To learn about jobs and work, do you (does PERSON) go to classes, work at a job, or do both?

CIRCLE ONE

CLASSES ONLY01 (SKIP TO Q.I40)

JOB ONLY02

BOTH CLASSES AND JOB0 3

DON'T KNOW-1 (SKIP TO Q.I40)

c. INTERVIEWER: IS THE ANSWER TO Q.I10, "YES"?

YES.01

NO00 (SKIP TO Q.I40)

d. Is this the job that you mentioned earlier or a different job?

SAME0 1

DIFFERENT.02

140. Are you (Is PERSON) in a (any other) program that teaches you
(him/her) about jobs and work?

Y E S 0 1

NO00 (SKIP TO Q.I42)

DON'T KNOW -1 (SKIP TO Q.I42)

141. a. To learn about jobs and work, do you (does PERSON) go to classes,
work at a job, or do both?

CLASSES ONLY01 (SKIP TO Q.I42)

JOB ONLY02

BOTH CLASSES AND JOB03

DON'T KNOW -1 (SKIP TO Q.I42)

b. **INTERVIEWER:** ARE **THE** ANSWERS TO Q.I10 = '01' OR Q.I39.b =
'02' OR '03'?

YES.01

NO00 (SKIP TO Q.I42)

c. Is this the same job that you just told me about or a different
job?

S A M E 0 1

DIFFERENT.02

142. **INTERVIEWER:** IS PERSON AGE 18 OR **OLDER?**

YES **.01**

NO. **.00** (SKIP TO Q.I44)

DON'T KNOW. **.-1** (SKIP TO Q.I44)

143. Are you now (IS PERSON)...

YES **NO** **DK**

Enrolled in continuing education
classes or night school. **.01** 00 -1

Enrolled in a GED program. **.01** 00 -1

OTHER DAY **ACTIVITY**

144. **INTERVIEWER:** ARE **THE** ANSWERS TO QUESTIONS 110, 132,
AND 140, "NO'?

YES. **.01** ,

NO **.00** (SKIP TO Q.I52)

145. You said that you are not (PERSON is not) currently working or going to school. Do you (Does PERSON) take part in some other day activity on a regular basis such as an adult day program or volunteer work?

ADULT DAY PROGRAM.02

VOLUNTEER WORK01 (SKIP TO Q.I52)

OTHER (SPECIFY).03 (SKIP TO Q.I52)

DON'T KNOW-1 (SKIP TO Q.I52)

146. During the past month, did you (PERSON) attend an adult day program such as a program at a habilitation or developmental activity center? (Do not include any school or training programs you already told me about.)

Y E S01

NO00 (SKIP TO Q.I52)

DON'T KNOW-1 (SKIP TO Q.I52)

147. How many days during the past month did you (PERSON) attend such a program?

!__!__ I DAYS

DON'T KNOW-1

148. a. Most of the time, when you go (PERSON goes) to such a program,
how do you (does PERSON) get there and back?

DRIVEN BY PARENTS/FRIENDS/HOUSEPARENTS . . .01
 PICKED UP IN VAN/CAR/SPECIAL BUS02
 TAXI03
 PUBLIC BUS/OTHER PUBLIC TRANSPORTATION . . .04
 WALK/BICYCLE05
 DRIVE(S) SELF.06
 OTHER (SPECIFY).07

DON'T KNOW-1

- b. Do you (Does PERSON) have any problems or concerns with
transportation to and from the adult day program?

YES.01
 NO00 (SKIP TO Q.I52)
 DON'T KNOW-1 (SKIP TO Q.I52)

- c. What problems or concerns do you (does PERSON) have?

PUBLIC TRANSPORTATION IS NOT AVAILABLE ..01
 PUBLIC TRANSPORTATION IS NOT ACCESSIBLE. .02
 SPECIAL TRANSPORTATION IS NOT AVAILABLE. .03
 NEEDS ASSISTANCE WITH TRAINING IN
 ARRANGING OR USING TRANSPORTATION. ...04
 TRANSPORTATION IS TOO COSTLY05
 TRANSPORTATION IS INCONVENIENT06
 TRANSPORTATION IS UNRELIABLE07
 OTHER (SPECIFY).08

DON'T KNOW-1

149. Are adult day programs provided as part of your (PERSON'S) living arrangement?

YES..... .01

NO00

DON'T KNOW-1

150. Did you (PERSON) and/or your (his/her) family have to pay for any of the costs of the adult day program?

YES.01

NO00 (SKIP TO Q.I52)

DON'T KNOW-1 (SKIP TO Q.I52)

151. In total, in the past month, how much did you (PERSON) and/or your (his/her) family have to pay for the adult day program?

\$ |__|__|__|__|

DON'T KNOW-1

152. Are you (Is PERSON) on a waiting list for an adult day program?

YES 0 1

NO0 0

DON'T KNOW-1

J. CATEGORICAL CONDITIONS

INTERVIEWER INSTRUCTIONS: ASK **Q.J2** IMMEDIATELY FOR EACH YES TO **Q.J1** WHEN INDICATED. TAKE EARLIEST AGE IF AGE DIFFERS FOR SYMPTOMS AND DIAGNOSIS/EVALUATION. ROUND AGE TO NEAREST YEAR. CODE BIRTH AS 00.

IF YES,

(S) **J1.** Have you (Has PERSON) ever been diagnosed or evaluated as having any of the following conditions?

(S) **J2.** How old were you (was PERSON) when you were (he/she was) first diagnosed or evaluated as having (CONDITION) or when symptoms first appeared?

	<u>YES</u>	<u>NO</u>	<u>DK</u>	<u>Age</u>	<u>DK</u>		YES	NO	DK
Asthma.01	00	-1	_ _ _ _	-1		01	00	-1
*Autism.01	00	-1	XXXXXXX	xx		XX	XX	XX
Birth Defects01	00	-1	XXXXXXX	XX		XX	XX	XX
*Cerebral Palsy.01	00	-1	* _ _ _ _	-1		01	00	-1
*Childhood Schizophrenia01	00	-1	* _ _ _ _	-1		01	00	-1
*Cystic Fibrosis01	00	-1	* _ _ _ _	-1		01	00	-1
*Developmental Delay01	00	-1	XXXXXXX	xx		X x	X x	X x

→ **PROBE:** WAS IT BEFORE
AGE 22?

NOTES: AGE IS NOT ASKED FOR CONDITIONS THAT **ARE** KNOWN TO **OCCUR** AT BIRTH.
CONDITIONS **ARE PRESENTED** IN **ALPHABETICAL ORDER** FOR **PURPOSES** OF **THE** PROTOTYPE **INSTRUMENT**.

IF YES,

J1. Have you (Has PERSON) ever been diagnosed or evaluated as having any of the following conditions?

	<u>YES</u>	<u>NO</u>	<u>DK</u>
*Down Syndrome.	01	00	-1
Epilepsy or Other Seizure Disorder.	01	00	-1
Head Injury or Trauma.	01	00	-1
Hearing Impairment - severe (e.g., deaf or hard of hearing with hearing aid)	01	00	-1
*Hydrocephalus.	01	00	-1
Inherited Disorders Affecting Development	01	00	-1
Infantile Paralysis (Polio). .	01	00	-1
*Mental Retardation	01	00	-1
Missing or Malformed Limbs ..	01	00	-1
Multiple Sclerosis (M.S.). . .	01	00	-1
*Muscular Dystrophy (M.D.). ..	01	00	-1
Paralysis of Limb(s), Neck. or Head	01	00	-1

J2. How old were you (was PERSON) when you were (he/she was) first diagnosed or evaluated as having (condition) or when symptoms first appeared?

<u>Age</u>	<u>DK</u>	<u>PROBE:</u> WAS IT BEFORE AGE 22?	<u>YES</u>	<u>NO</u>	<u>DK</u>
XXXXXXXX	XX		XX	XX	xx
_ _	-1		01	00	-1
_ _	-1		01	00	-1
_ _	-1		01	00	-1
* _ _	-1		01	00	-1
XXXXXXXX	xx		XX	XX	xx
_ _	-1		01	00	-1
* _ _	-1		01	00	-1
_ _	-1		01	00	-1
_ _	-1		01	00	-1
* _ _	-1		01	00	-1
_ _	-1		01	00	-1

IF YES,

J1. Have you (Has PERSON) ever been diagnosed or evaluated as having any of the following conditions?

	YES	NO	DK
Severe Emotional Disturbance or Mental Illness	01	00	-1
Sickle-Cell Anemia	01	00	-1
*Spina Bifida	01	00	-1
Spinal Cord Injury	01	00	-1
Visual Impairment - severe (e.g., blind or visually impaired even with glasses. .	01	00	-1
Any Other Serious Condition(s) Beginning Before Age 22 (SPECIFY)	01	00	-1

J2. How old were you (was PERSON) when you were (he/she was) first diagnosed or evaluated as having (condition) or when symptoms first appeared?

Age	DK	→ PROBE: WAS IT BEFORE AGE 22?		
		YES	NO	DK
_ _	-1	01	00	-1
XXXXXXXX	XX	XX	XX	XX
XXXXXXXX	XX	XX	XX	XX
_ _	-1	01	00	-1
_ _	-1	01	00	-1
_ _	-1	01	00	-1

**NOTES: (S) = SCREENING QUESTION; * = RESPONSE CATEGORIES TO
IDENTIFY PERSONS FOR FOLLOWUP SURVEY.**

K. HEALTH STATUS

- (C) K1. Would you say your (PERSON'S) health in general is excellent, very good, good, fair, or poor?

CIRCLE ONE

EXCELLENT01

VERY GOOD02

GOOD03

FAIR04

POOR05

DON'T KNOW.-1

- (C) K2. During the past 12 months, that is, since (12-month date) a year ago, about how many days did illness or injury keep you (PERSON) in bed more than half of the day? (Include days while an overnight patient in a hospital as well as days spent lying down or resting,)

|__|__| I' DAYS

DON'T KNOW.-1

- (C) K3. About how tall are you (is PERSON) without shoes?

_____ FEET _____ INCHES

DON'T KNOW.-1

- (C) K4. About how much do you (does PERSON) weigh without shoes?

|__|__|__| POUNDS

DON'T KNOW.-1

K5. a. Do you (Does PERSON) smoke cigarettes now?

YES 0 1

NO.00 (SKIP TO Q.K6)

DON'T KNOW. -1 (SKIP TO Q.K6)

b. On the average, about how many cigarettes a day do you (does
PERSON) now smoke?

I - ;_ ; CIGARETTES

DON'T KNOW. -1

NOTES: **MEDICAL CARE** UTILIZATION IS **COVERED** IN THE MODULE
ON MEDICAL AND HEALTH **SERVICES**.

PERSONS WITH CERTAIN CONDITIONS MAY NOT BE ABLE
TO **REPORT** HEIGHT **AND/OR WEIGHT DUE** TO DIFFICULTY
IN OBTAINING THESE **MEASUREMENTS**.

K6. I am going to read you another list of health conditions. As I read each condition, please tell me whether you now have (PERSON now has) this condition or if you (PERSON has) ever had the condition?

	<u>Now</u>			<u>Ever</u>		
	YES	<u>NO</u>	DK	<u>YES</u>	<u>NO</u>	<u>DK</u>
Alzheimer disease.	01	00	-1	01	00	-1
Anemia (chronic)	01	00	-1	01	00	-1
Arthritis.	01	00	-1	01	00	-1
Bedsores/pressure sores/other skin ulcers	01	00	-1	01	00	-1
Bladder or urinary tract infections.	01	00	-1	01	00	-1
Blood clots.	01	00	-1	01	00	-1
Broken bones (fractures)	01	00	-1	01	00	-1
Bronchitis (chronic)	01	00	-1	01	00	-1
Cancer/malignancy.	01	00	-1	01	00	-1
Cataract	01	00	-1	01	00	-1
Circulation problems including varicose veins	01	00	-1	01	00	-1
Constipation (frequent, severe).	01	00	-1	01	00	-1
Curvature or dislocation of the spine.	01	00	-1	01	00	-1
Diabetes	01	00	-1	01	00	-1
Elevated (high) blood cholesterol.	01	00	-1	01	00	-1
Emphysema.	01	00	-1	01	00	-1
Gallbladder problems	01	00	-1	01	00	-1
Glaucoma	01	00	-1	01	00	-1
Hearing impairment (mild/moderate)	01	00	-1	01	00	-1
Heart conditions/problems.	01	00	-1	01	00	-1

	<u>Now</u>			<u>Ever</u>		
	<u>YES</u>	<u>NO</u>	<u>DK</u>	<u>YES</u>	<u>NO</u>	<u>DK</u>
Hepatitis.	01	00	-1	01	00	-1
Hernia	01	00	-1	01	00	-1
High blood pressure.	01	00	-1	01	00	-1
Stomach ulcer.	01	00	-1	01	00	-1
Pneumonia.	01	00	-1	01	00	-1
Prostate problems (males only)	01	00	-1	01	00	-1
Skin rashes/infections (chronic)	01	00	-1	01	00	-1
Stroke	01	00	-1	01	00	-1
Thyroid disorders.	01	00	-1	01	00	-1
Visual impairment (mild/moderate).	01	00	-1	01	00	-1

NOTE: CONDITIONS ARE PRESENTED IN ALPHABETICAL
ORDER FOR PURPOSES OF THE PROTOTYPE
INSTRUMENT.

NOTE: C = **NEHS** Core Questionnaire item.

L. MEDICAL AND HEALTH SERVICES

- (C) L1. a. During the past 12 months, ABOUT how many times did you (PERSON) see or talk to a medical doctor or assistant? (Do not count doctors seen while an overnight patient in a hospital, but include any visits at home, in a doctor's office **or** clinic, or in an emergency room or center.)

|__|__| TIMES

DON'T KNOW.-1

- b. INTERVIEWER: **ARE ANY DOCTOR VISITS REPORTED?**

YES01

NO.00 (SKIP TO Q.L2)

- c. How many times in the past 12 months did you (PERSON) see or talk to an orthopedist? (SUBTRACT OUT THESE VISITS, IF NECESSARY, FROM Q.L1.a)

|_ I _| TIMES

DON'T KNOW. -1

- d. How many times in the past 12 months did you (PERSON) see or talk to a psychiatrist? (SUBTRACT OUT THESE VISITS, IF NECESSARY, FROM Q.L1.a)

|__|__| TIMES

DON'T KNOW. -1

- e. How many times in the past 12 months did you (PERSON) see or talk to other medical doctors or assistants?

|__|__| TIMES

DON'T KNOW. - 1

NOTE: THE NHIS COLLECTS DETAILED **INFORMATION** REGARDING DOCTOR VISITS FOR A **TWO-WEEK** REFERENCE PERIOD INCLUDING DATA ON VISITS TO THE **EMERGENCY ROOM**.

- f. Who paid or is expected to pay for your (PERSON'S) doctor visit(s) during the past 12 months?

CIRCLE ALL THAT APPLY

You (PERSON) and/or your (his/her) family . .01
Medicare or Medicare HMO.02
Medicaid.03
Veteran's benefits.04
CHAMPUS or CHAMPVA.05
Private insurance or non-Medicare HMO06
OTHER (SPECIFY)07

No cost to you (PERSON) and/or your
(his/her) family or to third party
payor08
Included as part of residential services. . .09
DON'T KNOW.-1

g. INTERVIEWER: WILL ANY OF THE COSTS FOR (THIS/THESE)
DOCTOR VISIT(S) BE PAID BY PERSON
AND/OR HIS/HER **FAMILY?**

YES01
NO00 (SKIP TO Q.L1.j)
DON'T KNOW..... -1 (SKIP TO Q.L1.j)

- h. In total, in the past 12 months, how much did you (PERSON) and/or your (his/her) family have to pay for (this/these) doctor visit(s), excluding costs that will be paid back by insurance?

\$ |__|__|__|__|__|

DON'T KNOW. -1

- i. Where do **you** (does PERSON) usually receive health care?

CIRCLE ONE

DOCTOR'S OFFICE01

CLINIC.02

HOSPITAL.03

OTHER (SPECIFY)04

DOCTOR ON STAFF AT RESIDENCE.05 (SKIP TO Q.L2)

DON'T KNOW. -1

- j. When you have gone (PERSON has gone) to the doctor in the past 12 months, how have you (has PERSON) usually gotten there and back?

CIRCLE ALL THAT APPLY

DRIVEN BY **PARENTS/FRIENDS/HOUSEPARENTS...** .01

PICKED UP IN VAN/CAR/SPECIAL BUS.02

TAXI.03

PUBLIC BUS/OTHER PUBLIC TRANSPORTATION. .. .04

WALK/BICYCLE.05

DRIVE(S) SELF06

AMBULANCE . . , 0 7

OTHER (SPECIFY)08

DON'T KNOW. -1

(C) L2. a. Since (13-month hospital date) a year ago, were you (was PERSON) a patient in the hospital overnight?

YES01

NO.00 (SKIP TO Q.L3)

DON'T KNOW.-1 (SKIP TO Q.L3)

(C) b. How many different times did you (PERSON) stay in any hospital overnight or longer since (13-month hospital date) a year ago?

|_| TIMES

DON'T KNOW.-1

c. Who paid or is expected to pay for all or part of the costs of your (PERSON'S) hospital stay(s)?

CIRCLE ALL THAT APPLY

You (PERSON) and/or your (his/her) family .01

Medicare or Medicare HMO. .02

Medicaid. .03

Veteran's benefits. .04

CHAMPUS or CHAMPVA. .05

Private insurance or non-Medicare HMO06

OTHER (SPECIFY) .07

No cost to you (PERSON) and/or your (his/her) family or to third party payor .08

Included as part of residential services. .09

DON'T KNOW.-1

d. **INTERVIEWER:** WILL **ANY** OF THE COSTS FOR (THIS/THESE)
HOSPITAL STAY(S) BE PAID BY **PERSON**
AND/OR HIS/HER FAMILY?

YES01

NO00 (SKIP TO Q.L3)

e. In total, since (NHIS **13-month** hospital date), how much did you
(PERSON) and/or your (his/her) family have to pay for
(this/these) hospital stay(s), excluding costs that will be
paid back by insurance?

\$ |__|__|__|__|__|

DON'T KNOW.-1

L3. a. Since (NHIS **13-month** hospital date), have you (has PERSON) been
placed temporarily outside the home overnight or longer for
behavior or mental health reasons? (Include placements in
hospitals or crisis centers.)

YES01

NO00 (SKIP TO Q.L4)

DON'T **KNOW**-1 (SKIP TO Q.L4)

b. How many times since (NHIS 13-month hospital date), have you (has
PERSON) been placed temporarily outside the home overnight or
longer for behavior or mental health reasons?

|__|__| TIMES

DON'T KNOW.-1

c. Who paid or is expected to pay for all or part of the costs of these placements?

CIRCLE ALL THAT APPLY

You (PERSON) and/or your (his/her) family . .01
Medicare or Medicare HMO.02
Medicaid.03
Veteran's benefits.04
CHAMPUS or CHAMPVA.0 5
Private insurance or non-Medicare HMO06
OTHER (SPECIFY)07

No cost to you (PERSON) and/or your
(his/her) family or to third party
payor08
Included as part of residential services. . .09
DON'T KNOW.-1

NOTE: ALTHOUGH THE NHIS ASKS ABOUT ALL OVERNIGHT
HOSPITALIZATIONS, QUESTION L3 IS INTENDED
TO COLLECT INFORMATION SPECIFICALLY ON
OUT-OF-HOME PLACEMENTS FOR MENTAL HEALTH
OR BEHAVIORAL REASONS.

d. INTERVIEWER: WILL ANY OF **THE** COSTS FOR THESE **PLACEMENTS**
BE PAID BY PERSON AND/OR **HIS/HER** FAMILY?

Y E S 0 1

NO.00 (SKIP TO Q.L4)

DON'T KNOW.-1 (SKIP TO Q.L4)

e. In total, since (NHIS **13-month** hospital date), how much did **you**
(PERSON) and/or your (his/her) family have to pay for these
placements, excluding costs that will be paid back by insurance?

\$ |__|__|__|__|

DON'T KNOW.-1

L4. a. In the past 12 months, have you (has PERSON) been a resident of
any nursing or convalescent home?

Y E S 0 1

NO.00 (SKIP TO Q.L5)

DON'T KNOW.-1 (SKIP TO Q.L5)

b. In total, how many days did you (PERSON) stay in a nursing or
convalescent home during the past 12 months?

|__|__|__| DAYS

DON'T KNOW.-1

c. Who paid or is expected to pay for all or part of the costs of your (PERSON'S) stay(s) in the nursing or convalescent home?

CIRCLE ALL THAT APPLY

You (PERSON) and/or your (his/her) family . . .01
Medicare or Medicare HMO.02
Medicaid.03
Veteran's benefits.04
CHAMPUS or CHAMPVA.0 5
Private insurance or non-Medicare HMO06
OTHER (SPECIFY)07

No cost to you (PERSON) and/or your
(his/her) family or to third party
payor08
Included as part of residential services. . .09
DON'T KNOW.-1

d. **INTERVIEWER:** WILL ANY OF THE COSTS FOR (THIS/THESE)
STAY(S) IN THE NURSING **OR** CONVALESCENT
HOME BE PAID BY PERSON AND/OR **(HIS/HER)**
FAMILY?

YES01
NO.00 (SKIP TO Q.L5)
DON'T KNOW.-1 (SKIP TO Q.L5)

e. In total, in the past 12 months, how much did you (PERSON) and/or your (his/her) family have to pay for (this/these) stay(s) in the nursing or convalescent home, excluding costs that will be paid back by insurance?

\$ |__|__|__|__|__|

DON'T KNOW. -1

L5. a. How many times have you (has PERSON) seen a dentist in the past 12 months?

|__|__| TIMES

DON'T KNOW. -1

b. INTERVIEWER: **ARE** ANY VISITS TO THE DENTIST REPORTED?

YES **.01**

NO00 (SKIP TO NEXT MODULE)

c. Who paid or is expected to pay for all or part of the costs of
(this/these) dental visit(s)?

CIRCLE ALL THAT APPLY

You (PERSON) and/or your (his/her) family . .01
Medicare or Medicare HMO.02
Medicaid.03
Veteran's benefits.04
CHAMPUS or CHAMPVA.05
Private insurance or non-Medicare HMO06
OTHER (SPECIFY)07

No cost to you (PERSON) and/or your
(his/her) family or to third party
payor08
Included as part of residential services. . .09
DON'T KNOW.-1

d. **INTERVIEWER: WILL ANY OF THE** COSTS FOR (THIS/THESE)
DENTAL VISIT(S) BE PAID BY PERSON AND/OR
HIS/HER FAMILY?
Y E S01
NO.00 (SKIP TO **NEXT** MODULE)
DON'T KNOW. .. .-1 (SKIP TO **NEXT** MODULE)

e. In total, in the past 12 months, how much did you (PERSON) and/or your (his/her) family have to pay for (this/these) dental visit(s), excluding costs that will be paid back by insurance?

\$ |__|__|__|__|__|

DON'T KNOW.-1

NOTE: C = **NHIS** Core **Questionnaire** item.

M. MENTAL HEALTH SERVICES

- M1. a. During the past month, did you (PERSON) have any visits with or attend any group sessions led by a mental health professional such as a psychologist, psychiatric nurse or psychiatric social worker? (Include any sessions with mental health professionals at your (PERSON'S) residence.)

YES01

NO.00 (SKIP TO Q.M2.a)

DON'T KNOW.-1 (SKIP TO Q.M2.a)

- b. How many visits or sessions did you (PERSON) have with such a mental health professional in the past month?

|__|__| VISITS/SESSIONS

DON'T KNOW.-1

- c. Were any of these visits or sessions provided through an agency or organization that **mostly** assists persons with mental retardation or developmental disabilities?

Y E S01

NO.00

DON'T KNOW.-1

M2. **INTERVIEWER:** IS PERSONAGE 0 THROUGH 5?

YES.01

NO00 (SKIP TO Q.M4)

- (S) M3. a. Does someone from a school or agency work with (PERSON) to help (PERSON) develop in such areas as moving around, talking, getting along with others, or learning?

*YES01

NO00

DON'T KNOW-1

- b. Does someone from a school or agency work with (PERSON'S) family to help them learn how to care for (PERSON'S) special needs?

*YES.01

NO00

DON'T KNOW-1

c. **INTERVIEWER:** IS THE ANSWER TO Q.M3.a OR Q.M3.b, "YES"?

YES.01

NO00 (SKIP TO Q.M4)

DON'T KNOW-1 (SKIP TO Q.M4)

d. How many times during the past month did someone from a school or agency work with (PERSON) and/or (his/her) family?

|__|__| TIMES

DON'T KNOW -1

e. Where did that usually take place?

IN (PERSON'S) RESIDENCE.01

IN A SCHOOL OR CENTER.02

IN A STAFF MEMBER'S PRIVATE OFFICE
(OUTSIDE OF A SCHOOL OR CENTER).03

OTHER (SPECIFY).04

DON'T KNOW -1

M4. **INTERVIEWER: IS PERSON AGE 6 OR OLDER?**

YES.01

N O00 (SKIP TO Q.M6)

(S) M5. a. Did someone from a school or agency work with you (PERSON) before you were (he/she was) 6 years old to help you (PERSON) develop in such areas as moving around, talking, or learning?

*YES.01

N O00

DON'T KNOW -1

- b. Did someone from a school or agency work with your (PERSON'S) family before you were (he/she was) 6 years old to help them learn how to care for your (PERSON'S) special needs?

* Y E S 0 1

N O00

DON'T KNOW -1

- M6. a. During the past month, did someone from a school or agency work with you (PERSON) and/or your (his/her) family to help you (PERSON) handle problems (at home or at work) or learn how to get along with other people?

Y E S 0 1

N O00 (SKIP TO Q.M6.d)

DON'T KNOW -1 (SKIP TO Q.M6.d)

- b. How many times in the past month did someone from a school or agency work with you (PERSON) and/or your (his/her) family?

!__!__!TIMES

DON'T KNOW -1

- c. Was this assistance provided through an agency or organization that mostly assists persons with mental retardation or developmental disabilities?

Y E S 0 1

N O 0 0

DON'T KNOW -1

d. **INTERVIEWER:** IS THE **ANSWER** TO Q.M1.a OR Q.M3.c, OR
Q.M6.a, "YES"?

YES.01

NO00 (SKIP TO NEXT MODULE)

M7. a. Who paid or is expected to pay for all or part of the costs of these services (including visits or sessions with mental health professionals and help in learning, handling problems, and getting along with others?)

CIRCLE ALL THAT APPLY

You (PERSON) and/or your (his/her)
family)01

Medicare or Medicare HMO.02

Medicaid.03

Veteran's benefits.04

CHAMPUS or CHAMPVA.05

Private insurance or non-Medicare HMO06

OTHER (SPECIFY)07

No cost to you (PERSON) or your (his/her)
family or to third party **payor**..... .08

Included as part of residential services. . .09

DON'T KNOW. -1

b. INTERVIEWER: **WILL** ANY OF THE COSTS FOR THESE MENTAL
HEALTH, **DEVELOPMENT**, OR BEHAVIOR **MANAGEMENT**
SERVICES BE PAID BY PERSON AND/OR HIS/HER
FAMILY?

YES01

NO00 (SKIP TO NEXT MODULE)

DON'T KNOW. . .-1 (SKIP TO NEXT MODULE)

c. In total, in the past month, how much did you (PERSON) and/or
your (his/her) family have to pay for these services, excluding
costs that will be paid back by insurance?

\$ |__|__|__|__|

DON'T KNOW.-1

N. CASE MANAGEMENT SERVICES

(S) N1. a. In the past 6 months, have you (has PERSON) had a case manager or someone from an agency or organization that you (he/she) could turn to for assistance?

*YES.01 (SKIP TO Q.N2.a)

NO00

DON'T KNOW -1

b. In the past 6 months, has someone from an agency or organization:

*
YES NO DK

Determined your (PERSON'S) eligibility for services.01 00 -1

Developed an individual plan of services for you (PERSON).01 00 -1

Made referrals for service for you (PERSON) or arranged for your (PERSON'S) placement in programs.01 00 -1

Assessed your (PERSON'S) progress in programs or with services.01 00 -1

Assisted you (PERSON) in solving problems.01 00 -1

c. **INTERVIEWER:** ARE ANT CASE MANAGEMENT SERVICES REPORTED IN Q.N1.b?

Y E S01

NO.00 (SKIP TO Q.N3)

N2. a. How many times in the past 6 months has a case manager or someone from an agency or organization provided you (PERSON) with (such) assistance?

{__}{__} TIMES

DON'T KNOW -1

b. Was this assistance provided by one person or more than one person?

ONE PERSON01 (SKIP TO NEXT MODULE)

MORE THAN ONE PERSON02

DON'TKNOW. -1 (SKIP TO NEXT MODULE)

c. Were these people all from one agency or were they from more than one agency?

ONE AGENCY01

MORE THAN ONE AGENCY02

DON'T KNOW -1

(S) d. (Does this agency/Do any of these agencies) mostly assist persons with mental retardation or developmental disabilities?

* Y E S01 (SKIP TO NEXT MODULE)

N O00 (SKIP TO NEXT MODULE)

DON'T KNOW. -1 (SKIP TO **NEXT** MODULE)

(S) N3. In the past 5 years, have you received any assistance from a case manager or any services such as housing or employment support from an agency or organization that mostly assists persons with mental retardation or developmental disabilities?

* Y E S 0 1
NO00
DON'T KNOW - 1

NOTES: (S) = SCREENING QUESTION; * = RESPONSE CATEGORIES USED TO IDENTIFY PERSONS FOR FOLLOWUP SURVEY.

0. FORMAL SUPPORT

INTERVIEWER: IS THIS A GROUP FACILITY (SEE **Q.A5**)? DO NOT
INCLUDE SUPERVISED APARTMENTS.

Y E S **.01** (SKIP TO MODULE **Q**)

NO. **.00**

01. Please tell me the names of any people--who do not live with you (PERSON)--but who come to help you (him/her) in your (his/her) home as part of their paid or volunteer work. These could be people who come from an agency or organization like a social worker or people you (PERSON) or your (PERSON'S) family hired privately. IF MORE THAN 5 NAMES ARE GIVEN, ASK ABOUT THE 5 WHO HELPED THE MOST.

IF "NONE", CHECK HERE AND SKIP TO NEXT MODULE **!__!**.

NAME 1:

NAME 2:

ASK Q.02-06 FOR EACH CAREGIVER NAMED. (PLEASE NOTE: Q.02 IS ON PGS. 1-2, Q.03-04 ON PGS. 3-4, Q.05-06 ON PGS. 5-6.)		
02. Is (NAME) from an agency or organization, someone you (PERSON) or your (his/her) family privately hired, or an employee of where you (he/she) live(s)?	AGENCY/ORGANIZATION.....01 PRIVATELY HIRED.....02 EMPLOYEE OF RESIDENCE.....03 DON'T KNOW.....-1	AGENCY/ORGANIZATION.....01 PRIVATELY HIRED.....02 EMPLOYEE OF RESIDENCE.....03 DON' T KNOW.....-1

NAME 3:

NAME 4:

NAME 5:

AGENCY/ORGANIZATION.....0 1	AGENCY/ORGANIZATION.....0 1	AGENCY/ORGANIZATION.....0 1
PRIVATELY HIRED.....0 2	PRIVATELY HIRED.....0 2	PRIVATELY HIRED.....0 2
EMPLOYEE OF RESIDENCE.....0 3	EMPLOYEE OF RESIDENCE.....0 3	EMPLOYEE OF RESIDENCE.....0 3
DON'T KNOW.....- 1	DON'T KNOW.....- 1	DON'T KNOW.....- 1

NAME 1:

NAME 2:

<p>03. What does (NAME) generally help you (him/her) with? (CIRCLE ALL THAT APPLY)</p> <p>IF NO MENTION OF PERSONAL CARE, ASK: Does (NAME) help you with eating, dressing, getting in or out of a bed or chair, bathing, or using the toilet?</p> <p>IF NO MENTION OF MEAL PREPARATION OR HOUSEWORK, ASK: Does (NAME) help with your meals, shopping, laundry, or other housework?</p>	<p>PERSONAL CARE..... 01</p> <p>PREPARING/DELIVERING MEALS..... 02</p> <p>HOUSEHOLD CHORES..... 03</p> <p>SHOPPING/RUNNING ERRANDS..... 04</p> <p>TAKING MEDICATION/HEALTH CARE 05</p> <p>MANAGING MONEY 06</p> <p>SUPERVISION 07</p> <p>MANAGING ASSISTIVE DEVICES..... 08</p> <p>SPEECH AND HEARING/PHYSICAL/ OCCUPATIONAL/THERAPY..... 09</p> <p>TAKING PERSON TO LEISURE ACTIVITIES (TRANSPORTATION OR SUPERVISION)..... 10</p> <p>TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... 11</p> <p>OTHER (SPECIFY)..... 12</p> <hr/> <p>DON'T KNOW..... -1</p>	<p>PERSONAL CARE.....01</p> <p>PREPARING/DELIVERING MEALS..... 02</p> <p>HOUSEHOLD CHORES.....03</p> <p>SHOPPING/RUNNING ERRANDS..... 04</p> <p>TAKING MEDICATION/HEALTH CARE05</p> <p>MANAGING MONEY..... 06</p> <p>SUPERVISION07</p> <p>MANAGING ASSISTIVE DEVICES..... 08</p> <p>SPEECH AND HEARING/PHYSICAL/ OCCUPATIONAL/THERAPY..... 09</p> <p>TAKING PERSON TO LEISURE ACTIVITIES (TRANSPORTATION OR SUPERVISION).....10</p> <p>TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... 11</p> <p>OTHER (SPECIFY).....12</p> <hr/> <p>DON'T KNOW..... -1</p>
<p>04. How many hours in a typical week or month does (NAME) come to your (his/her) home to help you (him/her)?</p>	<p> ____ ____ HOURS</p> <p>WEEK..... 01</p> <p>MONTH..... 02</p> <p>DON'T KNOW..... -1</p>	<p> ____ ____ HOURS</p> <p>WEEK..... 01</p> <p>MONTH..... 02</p> <p>DON'T KNOW..... -1</p>

NAME 3:

NAME 4:

NAME 5:

PERSONAL CARE.....01	PERSONAL CARE.....01	PERSONAL CARE.....01
PREPARING/DELIVERING MEALS.....02	PREPARING/DELIVERING MEALS.....02	PREPARING/DELIVERING MEALS.....02
HOUSEHOLD CHORES.....03	HOUSEHOLD CHORES.....03	HOUSEHOLD CHORES.....03
SHOPPING/RUNNING ERRANDS.....04	SHOPPING/RUNNING ERRANDS.....04	SHOPPING/RUNNING ERRANDS.....04
TAKING MEDICATION/HEALTH CARE.....05	TAKING MEDICATION/HEALTH CARE.....05	TAKING MEDICATION/HEALTH CARE.....05
MANAGING MONEY.....06	MANAGING MONEY.....06	MANAGING MONEY.....06
SUPERVISION.....07	SUPERVISION.....07	SUPERVISION.....07
MANAGING ASSISTIVE DEVICES.....08	MANAGING ASSISTIVE DEVICES.....08	MANAGING ASSISTIVE DEVICES.....08
SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY.....09	SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY.....09	SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY.....09
TAKING PERSON TO LEISURE ACTIVITIES (TRANSPORTATION OR SUPERVISION).....10	TAKING PERSON TO LEISURE ACTIVITIES (TRANSPORTATION & SUPERVISION).....10	TAKING PERSON TO LEISURE ACTIVITIES (TRANSPORTATION OR SUPERVISION).....10
TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION).....11	TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION).....11	TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION).....11
OTHER (SPECIFY).....12	OTHER (SPECIFY).....12	OTHER (SPECIFY).....12
DON'T KNOW.....-1	DON'T KNOW.....-1	DON'T KNOW.....-1
1 4 -1 -1 HOURS	1 -1 -1 -1 HOURS	1 1 1 1 HOURS
WEEK.....01	WEEK.....01	WEEK.....01
MONTH.....02	MONTH.....02	MONTH.....02
DON'T KNOW.....-1	DON'T KNOW.....-1	DON'T KNOW.....-1

NAME 1:

NAME 2:

05. Who paid or is expected to pay for all or part of the costs of (this/these) service(s)? (CIRCLE ALL THAT APPLY)	You (PERSON) and your (his/her) family (GO TO Q.6).....01 Medicare or Medicare HMD.....0 2 Medicaid.....0 3 Veteran's benefits.....0 4 CHAMPUS or CHANPVA.....0 5 Private insurance or non-Medicare HMO.....0 6 Other (SPECIFY)0 7	You (PERSON) and your (his/her) family (GO TO Q.6).....01 Medicare or Medicare HMD.....0 2 Medicaid.....0 3 Veteran's benefits.....0 4 CHAMPUS or CHAMPVA.....0 5 Private insurance or non-Medicare HMD.....0 6 Other (SPECIFY).....0 7
	No cost to you (PERSON) and/or your (his/her) family or to third party payor.....08 DON'T KNOW.....-1	No cost to you (PERSON) and/or your (his/her) family or to third party payor.....08 DON'T KNOW.....-1
06. In total, in the past month, how much did you (PERSON) and/or your (his/her) family have to pay for (this/these) services?	\$ _ _ _ _ DON'T KNOW.....-1	\$ _ _ _ _ DON'T KNOW.....-1

NAME 3:

NAME 4:

NAME 5:

You (PERSON) and your (his/her) family (GO TO Q.6).....01 Medicare or Medicare HMD.....02 Medicaid.....03 Veteran's benefits.....04 CHAMPUS or CHAMPVA.....05 Private insurance or non-Medicare HMD.....06 Other (SPECIFY).....07 <hr/> No cost to you (PERSON) and/ or your (his/her) family or to third party payor.....08 DON'T KNOW.....-1	You (PERSON) and your (his/her) family (GO TO Q.6).....01 Medicare or Medicare HMD.....02 Medicaid.....03 Veteran's benefits.....04 CHAMPUS or CHAMPVA.....05 Private insurance or non-Medicare HMD.....06 Other (SPECIFY).....07 <hr/> No cost to you (PERSON) and/ or your (his/her) family or to third party payor.....08 DON'T KNOW.....-1	You (PERSON) and your (his/her) family (GO TO Q.6).....01 Medicare or Medicare HMD.....02 Medicaid.....03 Veteran's benefits.....04 CHAMPUS or CHAMPVA.....05 Private insurance or non-Medicare HMD.....06 Other (SPECIFY).....07 <hr/> No cost to you (PERSON) and/ or your (his/her) family or to third party payor.....08 DON'T KNOW.....-1
\$ _ _ _ _ DON'T KNOW.....-1	\$ _ _ _ _ DON'T KNOW.....-1	\$ _ _ _ _ DON'T KNOW.....-1

P. LIVE-IN FORMAL SUPPORT

P1. The next questions are about people that--as part of their paid or volunteer jobs--live with you (PERSON) and help you (him/her) take care of yourself (him/herself): Please tell me the names of any people who are currently living with you because of their paid or volunteer work. IF MORE THAN 5 NAMES ARE GIVEN, ASK ABOUT THE 5 WHO HELPED THE MOST.

IF "NONE", CHECK HERE AND SKIP TO NEXT MODULE ____!

NAME 1:

NAME 2:

ASK Q.P2-P5 FOR EACH LIVE-IN CAREGIVER NAMED. (NOTE: Q.P2-P3 ARE ON PGS. 1-2, Q.P4-P5 ON PGS 3-4.)		
P2. Is (NAME) from an agency or organization, someone you (PERSON) or your (his/her) family privately hired, or an employee of the place where you (he/she) live(s)?	AGENCY/ORGANIZATION..... .01 PRIVATELY HIRED..... 0 2 EMPLOYEE OF RESIDENCE..... 0 3 DON'T KNOW..... -1	AGENCY/ORGANIZATION..... .01 PRIVATELY HIRED..... 0 2 EMPLOYEE OF RESIDENCE..... 0 3 DON'T KNOW..... -1
P3. What does (NAME) generally help you (him/her) with? (CIRCLE ALL THAT APPLY) IF NO MENTION OF PERSONAL CARE, ASK: Does (NAME) help you with eating, dressing, getting in or out of a bed or chair, bathing, or using the toilet? IF NO MENTION OF MEAL PREPARATION OR HOUSEWORK, ASK: Does (NAME) help with your meals, shopping, laundry, or other housework?	PERSONAL CARE..... .01 PREPARING/DELIVERING MEALS..... 0 2 HOUSEHOLD CHORES/LAUNDRY..... 0 3 SHOPPING/RUNNING ERRANDS..... 0 4 TAKING MEDICATION/HEALTH CARE..... .0 5 MANAGING MONEY..... 0 6 SUPERVISION0 7 MANAGING ASSISTIVE DEVICES..... 0 8 SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY..... 0 9 TAKING PERSON TO LEISURE ACTIVITIES (SUPERVISION OR TRANSPORTATION)10 TAKING PERSON TO PLACES/APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... 1 1 OTHER (SPECIFY)..... 1 2 DON'T KNOW..... -1	PERSONAL CARE..... .01 PREPARING/DELIVERING MEALS..... 0 2 HOUSEHOLD CHORES/LAUNDRY..... 0 3 SHOPPING/RUNNING ERRANDS..... 0 4 TAKING MEDICATION/HEALTH CARE..... 0 5 MANAGING MONEY..... 0 6 SUPERVISION..... 0 7 MANAGING ASSISTIVE DEVICES..... 0 8 SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY..... 0 9 TAKING PERSON TO LEISURE ACTIVITIES (SUPERVISION OR TRANSPORTATION)10 TAKING PERSON TO PLACES/APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... 1 1 OTHER (SPECIFY) 12 DON'T KNOW..... -1

NAME 3:

NAME 4:

NAME 5:

AGENCY/ORGANIZATION..... .01	AGENCY/ORGANIZATION..... .01	AGENCY/ORGANIZATION..... .01
PRIVATELY HIRED..... .02	PRIVATELY HIRED..... .02	PRIVATELY HIRED..... .02
EMPLOYEE OF RESIDENCE..... .03	EMPLOYEE OF RESIDENCE..... .03	EMPLOYEE OF RESIDENCE..... .03
DON'T KNOW..... -1	DON'T KNOW..... -1	DON'T KNOW..... -1
PERSONAL CARE..... .01	PERSONAL CARE..... .01	PERSONAL CARE..... .01
PREPARING/DELIVERING MEALS..... .02	PREPARING/DELIVERING MEALS..... .02	PREPARING/DELIVERING MEALS..... .02
HOUSEHOLD CHORES/LAUNDRY..... .03	HOUSEHOLD CHORES/LAUNDRY..... .03	HOUSEHOLD CHORES/LAUNDRY..... .03
SHOPPING/RUNNING ERRANDS..... .04	SHOPPING/RUNNING ERRANDS..... .04	SHOPPING/RUNNING ERRANDS..... .04
TAKING MEDICATION/HEALTH CARE..... .05	TAKING MEDICATION/HEALTH CARE..... .05	TAKING MEDICATION/HEALTH CARE..... .05
MANAGING MONEY..... .06	MANAGING MONEY..... .06	MANAGING MONEY..... .06
SUPERVISION..... .07	SUPERVISION..... .07	SUPERVISION..... .07
MANAGING ASSISTIVE DEVICES..... .08	MANAGING ASSISTIVE DEVICES..... .08	MANAGING ASSISTIVE DEVICES..... .08
SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY..... .09	SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY..... .09	SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL/THERAPY..... .09
TAKING PERSON TO LEISURE ACTIVITIES (SUPERVISION &TRANSPORTATION)..... .10	TAKING PERSON TO LEISURE ACTIVITIES (SUPERVISION &TRANSPORTATION)..... .10	TAKING PERSON TO LEISURE ACTIVITIES (SUPERVISION &TRANSPORTATION)..... .10
TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... .11	TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... .11	TAKING PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... .11
OTHER (SPECIFY)..... .12	OTHER (SPECIFY)..... .12	OTHER (SPECIFY)..... .12
DON'T KNOW..... -1	DON'T KNOW..... -1	DON'T KNOW..... -1

NAME 1:

NAME 2:

<p>P4. Who paid or is expected to pay for all or part of the costs of having (NAME) live with and help you (him/her)?</p> <p>(CIRCLE ALL THAT APPLY)</p>	<p>You (PERSON) and your (his/her) family (GO TO Q.5).....01</p> <p>Medicare or Medicare HMD.....02</p> <p>Medicaid.....03</p> <p>Veteran's benefits.....04</p> <p>CHAMPUS or CHAMPVA.....05</p> <p>Private insurance or non-Medicare HMD.....06</p> <p>Other (SPECIFY).....07</p> <hr/> <p>No cost to you (PERSON) and/or your (his/her) family or to third party payor.....08</p> <p>DON'T KNOW.....-1</p>	<p>You (PERSON) and your (his/her) family (GO TO Q.5).....01</p> <p>Medicare or Medicare HMD.....02</p> <p>Medicaid.....03</p> <p>Veteran's benefits.....04</p> <p>CHAMPUS or CHAMPVA.....05</p> <p>Private insurance or non-Medicare HMD.....06</p> <p>Other (SPECIFY).....07</p> <hr/> <p>No cost to you (PERSON) and/or your (his/her) family or to third party payor.....08</p> <p>DON'T KNOW.....-1</p>
<p>P5. In total, in the past month, how much did you (PERSON) and/or your (his/her) family have to pay for (this/these) services?</p>	<p>\$ </p> <p>DON'T KNOW.....-1</p>	<p>\$ </p> <p>DON'T KNOW.....-1</p>

NAME 3:

NAME 4:

NAME 5:

You (PERSON) and your (his/her) family (G 0 TO Q.5).....0 1 Medicare or Medicare HMO0 2 Medicaid0 3 Veteran's benefits0 4 CHAMPUS or CHAMPVA0 5 Private insurance or non-Medicare HMO0 6 Other (SPECIFY)0 7 <hr/> No cost to you (PERSON) and/ or your (his/her) family or to third party payor08 DON'T KNOW-1	You (PERSON) and your (his/her) family (G 0 TO Q.5).....0 1 Medicare or Medicare HMO0 2 Medicaid0 3 Veteran's benefits0 4 CHAMPUS or CHAMPVA0 5 Private insurance or non-Medicare HMO0 6 Other (SPECIFY)0 7 <hr/> No cost to you (PERSON) and/ or your (his/her) family or to third party payor08 DON'T KNOW-1	You (PERSON) and your (his/her) family (G 0 TO Q.5).....0 1 Medicare or Medicare HMO0 2 Medicaid0 3 Veteran's benefits0 4 CHAMPUS or CHAMPVA0 5 Private insurance or non-Medicare HMO0 6 Other (SPECIFY)0 7 <hr/> No cost to you (PERSON) and/ or your (his/her) family or to third party payor08 DON'T KNOW-1
\$ _ _ _ _ DON'T KNOW-1	\$ _ _ _ _ DON'T KNOW-1	\$ _ _ _ _ DON'T KNOW-1

Q. INFORMAL SUPPORT

Q1. Please tell me the names of any friends, relatives, or neighbors (IF PROXY: including yourself) who regularly help you (PERSON) with things like financial help, personal care (such as dressing or bathing), with medications, household chores, transportation, or who are with you to make sure you (he/she) don't need help with these kinds of things. Please remember I am asking about friends and relatives and not people who help you as part of their paid job or volunteer work. IF MORE THAN 5 NAMES GIVEN, ASK FOR THE 5 WHO HELPED THE MOST.

IF "NONE", CHECK HERE AND SKIP TO NEXT MODULE ☐.

NAME 1 _____ NAME 2 _____

ASK Q.02-Q9 FOR EACH INFORMAL CAREGIVER. (NOTE: Q.02-Q5 ARE ON PAGES 1-2, Q.06-Q10 PAGES 3-4.)		
Q2. How is (NAME) related to you (PERSON) ?	(write in) DON'T KNOW..... -1	(write in) DON'T KNOW..... -1
Q3. Is (NAME) a man or woman? (CODE WITHOUT ASKING, IF KNOWN.)	MALE..... 01 FEMALE..... 02 DON'T KNOW..... -1	MALE..... 01 FEMALE..... 02 DON'T KNOW..... -1
Q4. Does (NAME) currently live with you (PERSON)?	YES..... 01 NO..... 02 DON'T KNOW..... -1	YES..... 01 NO..... 02 DON'T KNOW..... -1
Q5. What does (NAME) usually help you (PERSON) with? (CIRCLE ALL THAT APPLY) IF NO MENTION OF PERSONAL CARE, ASK: Does (NAME) help you with eating, dressing, getting in or out of a bed or chair, bathing, or using the toilet? IF NO MENTION OF MEAL PREPARATION OR HOUSEWORK, ASK: Does (NAME) help with your meals, shopping, laundry, or other housework?	PERSONAL CARE..... 01 PREPARING/DELIVERING MEALS..... 02 HOUSEHOLD CHORES/LAUNDRY..... 03 SHOPPING/RUNNING ERRANDS..... 04 TAKING MEDICATION/HEALTH CARE..... 05 MANAGING MONEY..... 06 SUPERVISION..... 07 ASSISTIVE DEVICES..... 08 SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL THERAPY..... 09 TAKE PERSON TO LEISURE ACTIVITIES (SUPERVISION OR TRANSPORTATION)..... 10 TAKE PERSON TO PLACES/APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... 11 OTHER (SPECIFY)12 DON'T KNOW..... -1	PERSONAL CARE..... 01 PREPARING/DELIVERING MEALS..... 02 HOUSEHOLD CHORES/LAUNDRY..... 03 SHOPPING/RUNNING ERRANDS..... 04 TAKING MEDICATION/HEALTH CARE..... 05 MANAGING MONEY..... 06 SUPERVISION..... 07 ASSISTIVE DEVICES..... 08 SPEECH AND HEARING/PHYSICAL/OCCUPATIONAL THERAPY..... 09 TAKE PERSON TO LEISURE ACTIVITIES (SUPERVISION OR TRANSPORTATION)..... 10 TAKE PERSON TO PLACES/APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... 11 OTHER (SPECIFY)12 DON'T KNOW..... -1

NAME 3 _____ NAME 4 _____ NAME 5 _____

(write in)	(write in)	(Write in)
DON' T KNOW..... -1	DON' T KNOW..... -1	DON' T KNOW..... - 1
MALE..... 01	MALE..... 01	MALE..... 01
FEMALE..... 0 2	FEMALE..... 0 2	FEMALE..... 0 2
DON' T KNOW..... -1	DON' T KNOW..... -1	DON' T KNOW..... -1
YES..... 01	YES. ..*..... 01	YES..... 01
NO..... 02	NO..... 02	NO..... 02
DON' T KNOW..... -1	DON' T KNOW..... -1	DON' T KNOW..... -1
PERSONAL CARE..... 01	PERSONAL CARE..... .01	PERSONAL CARE..... .01
PREPARING/DELIVERING MEALS.....0 2	PREPARING/DELIVERING MEALS..... 0 2	PREPARING/DELIVERING MEALS.....02
HOUSEHOLD CHORES/LAUNDRY..... 0 3	HOUSEHOLD CHORES/LAUNDRY..... 0 3	HOUSEHOLD CHORES/LAUNDRY.....03
SHOPPING/RUNNING ERRANDS..... 0 4	SHOPPING/RUNNING ERRANDS..... 0 4	SHOPPING/RUNNING ERRANDS.....04
TAKING MEDICATION/ HEALTH CARE.....05	TAKING MEDICATION/ HEALTH CARE.....05	TAKING MEDICATION/ HEALTH CARE..... 05
MANAGING MONEY.....06	MANAGING MONEY.....06	MANAGING MONEY.....0 6
SUPERVISION..... ,07	SUPERVISION..... ,07	SUPERVISION..... ,0 7
ASSISTIVE DEVICES.....08	ASSISTIVE DEVICES.....08	ASSISTIVE DEVICES.....0 8
SPEECH AND HEARING/PHYSICAL/ OCCUPATIONAL THERAPY.....09	SPEECH AND HEARING/PHYSICAL/ OCCUPATIONAL THERAPY.....09	SPEECH AND HEARING/PHYSICAL/ OCCUPATIONAL THERAPY.....0 9
TAKE PERSON TO LEISURE ACTIVITIES (SUPERVISION OR TRANSPORTATION)..... .10	TAKE PERSON TO LEISURE ACTIVITIES (SUPERVISION OR TRANSPORTATION)..... .10	TAKE PERSON TO LEISURE ACTIVITIES (SUPERVISION OR TRANSPORTATION)..... .10
TAKE PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... .11	TAKE PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... .11	TAKE PERSON TO PLACES/ APPOINTMENTS (SUPERVISION OR TRANSPORTATION)..... .11
OTHER (SPECIFY).....12	OTHER (SPECIFY)..... 12	OTHER (SPECIFY)..... 12
DON' T KNOW..... -1	DON' T KNOW..... - 1	DON' T KNOW..... - 1

DRAFT - MODQ

NAME 1 _____ NAME 2 _____

<p>Q6. Does (NAME) usually help on weekdays (that is, Monday through Friday) or on the weekends (that is, Saturday or Sunday)? And, is it usually in the day or evening?</p> <p>CIRCLE ALL THAT APPLY.</p>	<p><u>WEEKDAYS</u></p> <p>DURING THE DAY..... 0 1</p> <p>IN THE EVENING..... 0 2</p> <p>DON'T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p>DURING THE DAY..... 0 3</p> <p>IN THE EVENING..... 0 4</p> <p>DON'T KNOW..... -1</p>	<p><u>WEEKDAYS</u></p> <p>DURING THE DAY..... 0 1</p> <p>IN THE EVENING..... 0 2</p> <p>DON'T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p>DURING THE DAY..... 0 3</p> <p>IN THE EVENING..... 0 4</p> <p>DON'T KNOW..... -1</p>
<p>Q7. And, how many hours does (NAME) spend helping you (him/her) (during the week/ on weekends)?</p>	<p><u>WEEKDAYS</u></p> <p>_____ HOURS</p> <p>DON'T KNOW..... - 1</p> <p><u>WEEKENDS</u></p> <p>_____ HOURS</p> <p>DON'T KNOW..... - 1</p>	<p><u>WEEKDAYS</u></p> <p>_____ HOURS</p> <p>DON'T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p>_____ HOURS</p> <p>DON'T KNOW..... -1</p>
<p>Q8. INTERVIEWER: IS (PERSON) AGE 18 OR OLDER?</p>	<p>YES..... (AS K Q.Q9).....0 1</p> <p>NO.... (SKIP TO NEXT COLUMN)....0 2</p>	<p>YES..... (AS K Q.Q9)..... 01</p> <p>NO... (SKI P TO NEXT COLUMN)....0 2</p>
<p>Q9. Does (NAME) ever help you (him/her) by giving you (him/her) cash, by paying some of your (his/her) bills, or buying things for you (him/her)?</p>	<p>YES..... 01</p> <p>NO.... (SKIP TO NEXT COLUMN).... 0 2</p> <p>DON'T KNOW....(SKI P TO NEXT NEXT COLUMN) -1</p>	<p>YES..... 01</p> <p>NO... (SKI P TO NEXT COLUMN).... 0 2</p> <p>DON'T KNOW... (SKI P TO NEXT NEXT COLUMN) -1</p>
<p>Q10. In an average week or month, about how much money does (NAME) give you (him/her) or spend on things for you (him/her)?</p>	<p>\$ _____</p> <p>PER WEEK..... 0 1</p> <p>PER MONTH..... 0 2</p> <p>DON'T KNOW..... - 1</p>	<p>\$ _____</p> <p>PER WEEK..... 0 1</p> <p>PER MONTH..... 0 2</p> <p>DON'T KNOW..... -1</p>

DRAFT - MODQ

MRDD-Q.QUE (QUE)

Q.3

2/27/90

NAME 3 _____ NAME 4 _____ NAME 5 _____

<p><u>WEEKDAYS</u></p> <p>DURING THE DAY..... .01</p> <p>IN THE EVENING..... .0 2</p> <p>DON' T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p>DURING THE DAY..... .0 3</p> <p>IN THE EVENING..... .0 4</p> <p>DON' T KNOW..... -1</p>	<p><u>WEEKDAYS</u></p> <p>DURING THE DAY.....0 1</p> <p>IN THE EVENING..... 0 2</p> <p>DON' T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p>DURING THE DAY..... .0 3</p> <p>IN THE EVENING..... .0 4</p> <p>DON' T KNOW..... -1</p>	<p><u>WEEKDAYS</u></p> <p>DURING THE DAY..... .0 1</p> <p>IN THE EVENING..... 0 2</p> <p>DON' T KNOW..... - 1</p> <p><u>WEEKENDS</u></p> <p>DURING THE DAY.....0 3</p> <p>IN THE EVENING..... .0 4</p> <p>DON' T KNOW.....- 1</p>
<p><u>WEEKDAYS</u></p> <p> _ _ _ HOURS</p> <p>DON' T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p> _ _ _ HOURS</p> <p>DON' T KNOW..... -1</p>	<p><u>WEEKDAYS</u></p> <p> _ _ _ HOURS</p> <p>DON' T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p> _ _ _ HOURS</p> <p>DON' T KNOW..... -1</p>	<p><u>WEEKDAYS</u></p> <p> _ _ _ HOURS</p> <p>DON' T KNOW..... -1</p> <p><u>WEEKENDS</u></p> <p> _ _ _ HOURS</p> <p>DON' T KNOW..... -1</p>
<p>YES (ASK Q.Q9).....01</p> <p>NO.... (SKIP TO NEXT COLUMN)....02</p>	<p>YES (ASK Q.Q9).....01</p> <p>NO.... (SKIP TO NEXT COLUMN)....02</p>	<p>YES..... (ASK Q.Q9).....01</p> <p>NO.... (SKIP TO NEXT COLUMN)....02</p>
<p>YES..... 01</p> <p>NO.... (SKIP TO NEXT COLUMN)....02</p> <p>DON' T KNOW... (SKIP TO NEXT NEXT COLUMN).... -1</p>	<p>YES.....*..... 01</p> <p>NO.... (SKIP TO NEXT COLUMN)....02</p> <p>DON' T KNOW. . ..(SKIP TO NEXT NEXT COLUMN).... -1</p>	<p>YES.....01</p> <p>NO.... (SKIP TO NEXT COLUMN)....02</p> <p>DON' T KNOW.. (SKIP TO Q.Q11)....-1</p>
<p>\$ _ _ _ _ _ . _ _ _ </p> <p>PER WEEK..... .01</p> <p>PER MONTH..... 0 2</p> <p>DON' T KNOW..... -1</p>	<p>\$ _ _ _ _ _ . _ _ _ </p> <p>PER WEEK..... .01</p> <p>PER MONTH..... 0 2</p> <p>DON' T KNOW..... -1</p>	<p>\$ _ _ _ _ _ . _ _ _ </p> <p>PER WEEK..... .01</p> <p>PER MONTH..... 02</p> <p>DON' T KNOW..... -1</p>

Q11. INTERVIEWER: **ARE ANY** INFORMAL **CAREGIVERS** A RELATIVE
WHO LIVES WITH PERSON?

YES01

NO.00 (SKIP TO NEXT MODULE)

Q12. In the past six months, has someone other than family members helped
you (PERSON) for a period of time so that the people you live (he/she
lives) with could go out or take a break?

YES.01

N O00 (SKIP TO **NEXT** MODULE)

DON'T KNOW.-1 (SKIP TO NEXT MODULE)

413. How many times in the past six months has someone other than family
members done that?

|_|_| TIMES

DON'T KNOW.-1

414. How long did (this/each) time usually last?

|_|_|

H O U R S 0 1

DAYS.02

DON'T KNOW.-1

Q15. Where did you (PERSON) usually 'stay during (that time/those times)?

IN (PERSON'S) HOME.01

IN THE CAREGIVER'S HOME02

AT A DAY CARE CENTER.03

IN A GROUP HOME04

AT A HOSPITAL OR NURSING
HOME (SPECIFY).05

OTHER (SPECIFY)06

DON'T KNOW.-1

R. SOCIAL INTERACTION/BEHAVIOR

R.1 INTERVIEWER: IS PERSON AGE 5 OR **OLDER?**

YES01

NO00 (SKIP TO NEXT MODULE)

R2. During the past week, how many times did you (PERSON) talk on the phone for five minutes or longer with...

a. family members who do not live with you (him/her)?

|__|__| TIMES

DON'T KNOW:-1

b. friends who do not live with you (him/her)? (Do not include staff members or counselors.)

|__|__| TIMES

DON'T KNOW.-1

R3. During the past week, how many times did you (PERSON) talk in-person or have visits with...

a. family members who do not live with you (him/her)?

|__|__| TIMES

DON'T KNOW.-1

b. friends who do not live with you (him/her)? (Do not include staff members or counselors.)

|__|__| TIMES

DON'T KNOW.-1

R4. **INTERVIEWER: ARE** ANY IN-PERSON CONVERSATIONS OR VISITS
REPORTED IN Q.R3.a or Q.R3.b?

YES.01

NO00 (SKIP TO Q.R6)

R5. a. Where did these in-person conversations or visits usually take place?

CIRCLE ONE

In your (PERSON'S) residence.01 (SKIP TO Q.R6)

In other person's residence02

In school03 (SKIP TO Q.R6)

At work04 (SKIP TO Q.R6)

Other public place.05

DON'T KNOW.-1 (SKIP TO Q.R6)

b. Most of the time, when you visit (PERSON visits) with family members or friends in another person's residence, or in a public place other than school or work, how do you (does PERSON) get there and back?

CIRCLE ALL THAT APPLY

DRIVEN BY **PARENTS/FRIENDS/HOUSEPARENTS...** .01

PICKED UP IN VAN/CAR/SPECIAL BUS.02

TAXI03

PUBLIC BUS/OTHER PUBLIC TRANSPORTATION. ..04

WALK/BICYCLE.05

DRIVE(S) SELF06

OTHER (SPECIFY)07

DON'T KNOW.-1

c. Do you (Does PERSON) have any problems or concerns with transportation to and from these places?

YES..... .01

NO.00 (SKIP TO Q.R6)

DON'T KNOW.-1 (SKIP TO Q.R6)

d. What problems or concerns do you (does PERSON) have?

PUBLIC TRANSPORTATION IS NOT AVAILABLE. . . .01

PUBLIC TRANSPORTATION IS NOT ACCESSIBLE . . .02

SPECIAL TRANSPORTATION IS NOT AVAILABLE . . .03

NEEDS ASSISTANCE WITH TRAINING IN **ARRANGING**
OR USING TRANSPORTATION04

TRANSPORTATION IS TOO COSTLY.05

TRANSPORTATION IS INCONVENIENT.06

TRANSPORTATION IS UNRELIABLE.07

OTHER (SPECIFY)08

DON'T KNOW.-1

R6. INTERVIEWER: ARE ANY CONVERSATIONS OR VISITS WITH
FRIENDS REPORTED IN **Q.R2.b** OR **Q.R3.b**?

YES.01

NO00 (SKIP TO Q.R8)

R7. a. You mentioned that during the past week you (PERSON) talked with friends either on the phone or in-person. How many friends did you (he/she) talk to? (Do not include staff members or counselors.)

|__|__| FRIENDS

DON'T KNOW. -1 (SKIP TO Q.R8)

b. How many of these friends have disabilities or impairments?

|__|__| FRIENDS

DON'T KNOW. -1

c. How many of these friends do not have disabilities or impairments?

|__|__| FRIENDS

DON'T KNOW. -1

R8. a. Old you (PERSON) do any of the following during the past month:

	<u>YES</u>	<u>NO</u>	<u>OK</u>
Go to a store, shopping center, or mall	01	00	-1
Go out to eat	01	00	-1
Go to a movie, play, or concert..	01	00	-1
Go to church or synagogue	01	00	-1
Participate in sports	01	00	-1
Attend sporting events as a spectator.	01	00	-1
Attend a party, dance, or group social gathering.	01	00	-1
Visit a museum or library	01	00	-1
Go to meetings of clubs or organizations.	01	00	-1
Go on a date.	01	00	-1

IF YES:

b. Who else, if anyone, usually took part in this activity?

	Family Member	Friends With Disabilities or Impairments	Friends With No Disabilities or Impairments	Paid or Volunteer Staff	By Self	<u>OK</u>
	01	02	03	04	05	-1
	01	02	03	04	05	-1
	01	02	03	04	05	-1
	01	02	03	04	05	-1
	01	02	03	04	05	-1
	01	02	03	04	05	-1
	01	02	03	04	05	-1
	01	02	03	04	05	-1
	01	02	03	04	05	-1

R9. INTERVIEWER: DID PERSON PARTICIPATE IN ONE OR MORE ACTIVITIES IN Q.R8.a?

YES.01

NO00 (SKIP TO Q.R11)

DON'T KNOW-1 (SKIP TO Q.R11)

- R10. a. Most of the time when you go (PERSON goes) to (READ SPECIFIC ACTIVITY/ACTIVITIES MENTIONED), how do you (does PERSON) get there and back?

CIRCLE ALL THAT APPLY

DRIVEN BY PARENTS/FRIENDS/HOUSEPARENTS. . . .01
PICKED UP IN VAN/CAR/SPECIAL BUS.02
TAXI.....03
PUBLIC BUS/OTHER PUBLIC TRANSPORTATION. ..04
WALK/BICYCLE.05
DRIVE(S) SELF06
OTHER (SPECIFY)07

DON'T KNOW.-1

- b. Do you (Does PERSON) have any problems or concerns with transportation to and from (this activity/these activities)?

Y E S 0 1
NO.00 (SKIP TO Q.R11)
DON'T KNOW. -1 (SKIP TO Q.R11)

- c. What problems or concerns do you (does PERSON) have?

PUBLIC TRANSPORTATION IS NOT AVAILABLE. . . .01
PUBLIC TRANSPORTATION IS NOT ACCESSIBLE ..02
SPECIAL TRANSPORTATION IS NOT AVAILABLE ..03
NEEDS ASSISTANCE WITH TRAINING IN ARRANGING
OR USING TRANSPORTATION04
TRANSPORTATION IS TOO COSTLY.05
TRANSPORTATION IS INCONVENIENT.06
TRANSPORTATION IS UNRELIABLE.07
OTHER (SPECIFY)08

DON'T KNOW.-1

(S) R11. a. Do you (Does PERSON) usually decide what you do (he/she does) on weekends and evenings for fun or are those decisions made by someone else?

CIRCLE ONE

RESPONDENT MAKES CHOICE01 (SKIP TO Q.R12)

*SOMEONE ELSE MAKES CHOICE02 (SKIP TO Q.R11.b)

DON'T KNOW.-1 (SKIP TO Q.R12)

b. Who makes this decision for you (PERSON)?

CIRCLE ALL THAT APPLY

PERSONAL FRIEND (UNPAID).01

FAMILYMEMBER.02

LEGAL GUARDIAN.03

AGENCY OR SCHOOL STAFF MEMBER04

RESIDENTIAL STAFF05

OTHER (SPECIFY)06

DON'T KNOW.-1

R12. INTERVIEWER: IS PERSON AGE 18 **OR** OLDER?

YES.01

NO00 (SKIP TO NEXT MODULE)

R13. During the past month, did you (PERSON) do any of the following?

	<u>YES</u>	<u>NO</u>	<u>DK</u>
Attempt to injure yourself (him/herself). .	01	00	-1
Display physical violence toward others ..	01	00	-1
Threaten others with physical violence in words or gestures.	01	00	-1
Damage your (his/her) property or property of other persons	01	00	-1
Disrupt others' activities.	01	00	-1
Scream, yell, or cry inappropriately. ...	01	00	-1
Become very angry, have temper tantrums ..	01	00	-1
Engage in other socially unacceptable behavior (lying, stealing).	01	00	-1
Display unusual, repetitive movements or habits	01	00	-1
Repeat a word or phrase over And over ...	01	00	-1
Withdraw or act inattentive, listless, unresponsive.	01	00	-1
Act uncooperatively (ignore regulations, resist instructions).	01	00	-1
Act restless (unable to sit still or concentrate).	01	00	-1
Run or wander away.	01	00	-1

IF YES,

R14. How many times did you (PERSON) (do mentioned behavior) In the past month?

<u>Daily</u>	<u>Several Times Per Week</u>	<u>Several Times Per Month</u>	<u>DK</u>
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1
01	02	03	-1

NOTE: QUESTION R13 IS ADAPTED FROM THE TEMPLE
UNIVERSITY BEHAVIOR DEVELOPMENT INSTRUMENT.

S. CHILD MODULE: DEVELOPMENTAL MILESTONES AND BEHAVIOR

S1. a. INTERVIEWER: IS PERSON AGE 4 YEARS OR YOUNGER?

YES01

NO.00 (SKIP TO Q.S51.a)

S1. b. INTERVIEWER:

REFER TO AGE OF SAMPLE CHILD.

AFTER MARKING THE APPROPRIATE BOX, GO TO THE LIST OF QUESTIONS AND CIRCLE THE CORRESPONDING QUESTION NUMBERS.

ASK FOR SEQUENCE OF QUESTIONS UNTIL FIVE CONSECUTIVE "YES" RESPONSES ARE GIVEN, THEN ASK SECOND SEQUENCE OF QUESTIONS UNTIL FIVE CONSECUTIVE "NO" RESPONSES ARE GIVEN. ONE OR MORE OF THE FIVE CONSECUTIVE "NO" RESPONSES MAY HAVE BEEN GIVEN AT THE BEGINNING OF THE FIRST SEQUENCE, THUS REQUIRING LESS THAN FIVE CONSECUTIVE "NO" RESPONSES IN THE SECOND SEQUENCE.

AFTER COMPLETING SECOND SEQUENCE, GO TO Q.S51.a. IF 10 CONSECUTIVE "NO" RESPONSES ARE GIVEN IN THE FIRST SEQUENCE, GO TO Q.S51.a WITHOUT ASKING ANY FURTHER QUESTIONS IN THE LIST.

AGE (CIRCLE ONLY ONE)	
01	<input type="checkbox"/> Under 4 Months
02	<input type="checkbox"/> 4 Months
03	<input type="checkbox"/> 5 Months
04	<input type="checkbox"/> 6 Months
05	<input type="checkbox"/> 7 Months
06	<input type="checkbox"/> 8 Months
07	<input type="checkbox"/> 9 Months
08	<input type="checkbox"/> 10 Months
09	<input type="checkbox"/> 11 Months
10	<input type="checkbox"/> 12-14 Months
11	<input type="checkbox"/> 15-17 Months
12	<input type="checkbox"/> 18-23 Months
13	<input type="checkbox"/> 2 Years
14	<input type="checkbox"/> 3 Years
15	<input type="checkbox"/> 4 Years

SEQUENCES	
1 DESCENDING ORDER BEGINNING WITH QUESTION NUMBER:	2 ASCENDING ORDER BEGINNING WITH QUESTION NUMBER:
6	7
8	9
10	11
12	13
14	15
16	17
18	19
20	21
22	23
24	25
28	29
33	34
36	37
41	42
44	45

Now I would like to ask a few questions about various things children do at different ages.

S1c.	When lying on (his/her) stomach, has (PERSON) ever turned (his/her) head from side to side?	01 Yes	02 No	-1 Don't Know
s2.	Have (PERSON'S) eyes ever followed a moving object at all?	01 Yes	02 No	-1 Don't Know
s3.	When lying on (PERSON'S) stomach on a flat surface did (he/she) ever lift (his/her) head off the surface for a moment?	01 Yes	02 No	-1 Don't Know
s4.	Have (PERSON'S) eyes ever followed a moving object all the way from one side to another?	01 Yes	02 No	-1 Don't Know
S5a.	Has (PERSON) ever smiled at someone when they talked to or smiled at (him/her) without being touched?	01 Yes	02 No	-1 Don't Know
b.	IF "YES," ASK: How old was (PERSON) when (he/she) first smiled at someone when they talked to or smiled at (him/her)?	Age	02 <input type="text"/> Weeks 03 <input type="text"/> Months	1- Don't Know
S6.	When lying on (his/her) stomach, has (PERSON) ever raised (his/her) head and chest from the surface while resting (his/her) weight on (his/her) lower arms or hands?	01 Yes	02 No	-1 Don't Know
S7.	While lying on (his/her) back and being pulled up to a sitting position, did (PERSON) ever hold (his/her)-head stiffly so that it did not hang back as (he/she) was pulled up?	01 Yes	02 No	-1 Don't Know
S8.	Has (PERSON) ever laughed out loud without being tickled or touched?	01 Yes	02 No	-1 Don't Know
S9.	Has (PERSON) ever turned (his/her) head around to look at something?	01 Yes	02 No	-1 Don't Know
S10.	Has (PERSON) ever held in one hand a moderate size object such as a block or a rattle?	01 Yes	02 No	-1 Don't Know
S11.	Has (PERSON) ever looked around with (his/her) eyes for a toy which was lost or not nearby?	01 Yes	02 No	-1 Don't Know
S12a.	Has (PERSON) ever rolled over on (his/her) own (on purpose)?	01 Yes	02 No	-1 Don't Know
b.	IF YES, ASK: How old was (he/she) when (he/she) first rolled over?	<u>Age</u>	02 <input type="text"/> Weeks 03 <input type="text"/> Months	-1 Don't Know
s13.	Has (PERSON) ever been pulled from a sitting to a standing position and supported (his/her) own weight with legs stretched out?	01 Yes	02 No	-1 Don't Know
s14.	Has (PERSON) ever sat alone with no help except for leaning forward on (his/her) hands or with just a little help from someone else?	01 Yes	02 No	-1 Don't Know
S15.	Has (PERSON) ever seemed to enjoy looking in the mirror at (himself/herself)?	01 Yes	02 No	-1 Don't Know
S16a.	Has (PERSON) ever said any recognizable words, such as "mama" or "dada"?	01 Yes	02 No	-1 Don't Know
b.	IF "YES", ASK: How old was (he/she) when (he/she) first said any recognizable words?	Age	02 <input type="text"/> Weeks 03 <input type="text"/> Months	-1 Don't Know

S17a. Has (PERSON) ever crawled when left lying on (his/her) stomach?	01 Yes	02 No	-1 Don't Know
b. IF "YES", ASK: How old was (he/she) when (he/she) first crawled?	Age	02 <input type="checkbox"/> Weeks 03 <input type="checkbox"/> Months	-1 Don't Know
S18. Did (PERSON) ever sit for 10 minutes without any support at all?	01 Yes	02 No	-1 Don't Know
S19. Has (PERSON) ever pulled (himself/herself) to a standing position without help from another person?	01 Yes	02 No	-1 Don't Know
S20. Has (PERSON) ever recognized (his/her) own name when someone said it?	01 Yes	02 No	-1 Don't Know
S21. Has (PERSON) ever picked up small objects, such as raisins or cookie crumbs, using only (his/her) thumb and first finger?	01 Yes	02 No	-1 Don't Know
S22a. Has (PERSON) ever waved good-bye without help from another person?	01 Yes	02 No	-1 Don't Know
b. IF "YES", ASK: How old was (he/she) when (he/she) first waved good-bye?	Age	02 <input type="checkbox"/> Weeks 03 <input type="checkbox"/> Months	-1 Don't Know
S23a. Has (PERSON) ever stood along on (his/her) feet for 10 seconds or more without holding on to anything or another person?	01 Yes	02 No	-1 Don't Know
b. IF "YES", ASK: How old was (he/she) when (he/she) first stood alone?	01 Yes	02 No	-1 Don't Know
S24. Has (PERSON) said 2 recognizable words besides "mama" and "dada"?	01 Yes	02 No	-1 Don't Know
S25. Has (PERSON) ever walked at least 2 steps with one hand held or holding onto something?	01 Yes	02 No	-1 Don't Know
S26. Has (PERSON) ever shown by (his/her) behavior that (he/she) knows the names of some common objects when somebody else names them out loud?	01 Yes	02 No	-1 Don't Know
S27. Has (PERSON) ever crawled up at least 2 stairs or steps?	01 Yes	02 No	-1 Don't Know
S28. Has (PERSON) ever said the name of a familiar object, such as a ball?	01 Yes	02 No	-1 Don't Know
S29a. Has (PERSON) ever walked at least 2 steps without holding on to anything or another person?	01 Yes	02 No	-1 Don't Know
b. IF "YES", ASK: How old was (he/she) when (he/she) first walked at least 2 steps?	Age	02 <input type="checkbox"/> Weeks 03 <input type="checkbox"/> Months	-1 Don't Know
S30. Has (PERSON) ever shown that (he/she) wanted something without crying or whining? It may have been by pointing, pulling, or making pleasant sounds.	01 Yes	02 No	-1 Don't Know
S31. Has (PERSON) ever made a line with a crayon or pencil?	01 Yes	02 No	-1 Don't Know
S32. Has (PERSON) ever run?	01 Yes	02 No	-1 Don't Know

s33.	Did (PERSON) ever walk up at least 2 stairs with one hand held or holding the railing?	01 Yes	02 No	-1 Don't Know
s34.	Has (PERSON) ever let someone know, without crying, that (he/she) was bothered by (his/her) pants or diapers being wet or soiled?	01 Yes	02 No	-1 Don't Know
S35.	Has (PERSON) ever fed (himself/herself) with a spoon or fork without spilling much?	01 Yes	02 No	-1 Don't Know
S36.	Has (PERSON) ever walked upstairs by (himself/herself) without holding on to a rail?	01 Yes	02 No	-1 Don't Know
s37.	Has (PERSON) ever spoken in a partial sentence of 3 words or more?	01 Yes	02 No	-1 Don't Know
S38.	Has (PERSON) ever said (his/her) first and last names together without someone's help? (NICKNAME MAY BE USED FOR FIRST NAME.)	01 Yes	02 No	-1 Don't Know
s39.	Has (PERSON) ever walked up stairs by (himself/herself) with no help, stepping on each step with only one foot?	01 Yes	02 No	-1 Don't Know
S40.	Has (PERSON) ever counted 3 objects?	01 Yes	02 No	-1 Don't Know
s41.	Has (PERSON) ever pedaled a tricycle at least 10 feet?	01 Yes	02 No	-1 Don't Know
S42.	Does (PERSON) know (his/her) own age and sex?	01 Yes	02 No	-1 Don't Know
s43.	Has (PERSON) ever washed and dried (his/her) hands without any help except for turning the water on and off?	01 Yes	02 No	-1 Don't Know
s44.	Has (PERSON) ever done a somersault without help from anybody?	01 Yes	02 No	-1 Don't Know
s45.	Has (PERSON) ever drawn a picture of a man or woman with at least 2 parts of the body besides a head?	01 Yes	02 No	-1 Don't Know
S46.	Has (PERSON) ever gone to the toilet alone?	01 Yes	02 No	-1 Don't Know
s47.	Has (PERSON) ever played with several children at the same time?	01 Yes	02 No	-1 Don't Know
S48.	Has (PERSON) ever said the names of at least 4 colors?	01 Yes	02 No	-1 Don't Know
s49.	Has (PERSON) ever dressed (himself/herself) without any help except for tying shoes (and buttoning the back of dresses)?	01 Yes	02 No	-1 Don't Know
S50.	Has (PERSON) ever counted out loud up to 10?	01 Yes	02 No	-1 Don't Know

NOTE: ~~SCREENING~~ CRITERIA FOR YOUNG CHILDREN COULD BE DEVELOPED USING THESE QUESTIONS.

S50. a. Which of the following behaviors best applies to (PERSON) in the past month?

CIRCLE ONE

a. Independent, not clinging, can easily
be left with people he/she knows.01

Gets upset if away from primary caregivers;
takes some time to get over it.02

Very clinging and dependent; can't be left with
others, continually demands to be with mother .. .03

DON'T KNOW.-1

b. Rarely demands more than his/her share of
attention01

Sometimes demands too much attention, but
can play alone.02

Continually demands too much attention,
follows mother around all day03

DON'T KNOW.-1

c. Easy to manage; not difficult to handle01

Sometimes difficult to manage, or out of control. .02

Frequently very difficult to manage or
handle, almost daily.03

DON'T ~~KNOW~~.-1

d. Usually easy to discipline.01

Sometimes difficult to discipline,
for short periods02

Frequently very hard to discipline;
frequently disobedient.03

DON'T KNOW.-1

- e. Doesn't have temper tantrums.01
- Sometimes has tantrums which last
a few minutes (1-2 a day)02
- Has frequent or long temper tantrums
(3 or more a day)03
- DON'T KNOW.-1
- f. Usually happy except for brief periods;
for example, when tired, hungry, or sick.01
- Sometimes miserable or irritable on
most days and for long periods.02
- Frequently miserable or irritable on
most days and for long periods.03
- DON'T KNOW.-1
- g. Not a worrier01
- Sometimes worries for short periods02
- Has many different worries, very anxious
about things; for example, accidents,
illness, monsters, changes.03
- DON'T KNOW.-1
- h. Rarely fearful, mild fears only01
- Somewhat fearful, several mild, or
1-2 strong fears.02
- Very fearful, has many strong fear reactions. ..03
- DON'T KNOW.-1

- i. Few problems getting along with brothers
and sisters01
- Some difficulties with brothers and sisters:
disrupts play at times.02
- Has serious difficulties getting along
with brothers or sisters; disrupts play
frequently.03
- DON'T KNOW. -1
- j. Gets along well with other children01
- Some difficulties playing with other children;
disrupts play at times.02
- Finds it very difficult to play with other
children; disrupts play frequently.03
- DON'T KNOW.-1

NOTE: QUESTIONS **S50a. a-j** **ARE** ADAPTED FROM THE
HEALTH AND DEVELOPMENTAL STATUS SECTION
OF THE 1990 **LONGITUDINAL FOLLOWUP** TO THE
NATIONAL MATERNAL AND INFANT HEALTH SURVEY.

S51. a. INTERVIEWER: IS PERSON **BETWEEN THE** AGES OF 4 AND
17 **YEARS?**

YES01

NO.00 (SKIP TO **NEXT** MODULE)

Now **I am** going to read some statements that describe behavior problems many children have. Please tell me whether each statement has been Often True, Sometimes **True**, or Not True of (PERSON) during the past 3 months.

The first statement is: "Has sudden changes in mood or feelings." Has that been Often True, Sometimes True, or Not True of (PERSON) in the past 3 months?

(RECORD RESPONSE AND CONTINUE WITH STATEMENT **S52.** READ LIST REPEATING CATEGORIES AND/OR TIME REFERENCE AS NEEDED.)

	<u>Often True</u>	<u>Sometimes True</u>	<u>Not True</u>
S51b. Has sudden changes in mood or feelings.	01	02	03
S52. Feels or complains that no one loves (him/her).	01	02	03
s53. Is rather high strung, tense, or nervous.	01	02	03
s54. Cheats or tells lies.	01	02	03
S55. Is too fearful or anxious.	01	02	03
S56. Argues too much.	01	02	03
S57. Has difficulty concentrating, cannot pay attention for long.	01	02	03
S58. Is easily confused, seems to be in a fog.	01	02	03
s59. Bullies, or is cruel or mean to others.	01	02	03
S60. Is disobedient at home.	01	02	03
S61. Is disobedient at school.	01	02	03
S62. Does not seem to feel sorry after (he/she) misbehaves.	01	02	03
S63. Has trouble getting along with other children.	01	02	03
S64. Has trouble getting along with teachers.	01	02	03
S65. Is impulsive, or acts without thinking.	01	02	03
S66. Feels worthless or inferior.	01	02	03

		<u>Often True</u>	<u>Sometimes True</u>	<u>Not True</u>
S67.	Is not liked by other children.	01	02	03
S68.	Has a lot of difficulty getting (his/her) mind off certain thoughts, has obsessions.	01	02	03
S69.	Is restless or overly active, cannot sit still.	01	02	03
S70.	Is stubborn, sullen, or irritable.	01	02	03
s71.	Has a very strong temper or loses it easily.	01	02	03
s72.	Is unhappy, sad or depressed.	01	02	03
s73.	Is withdrawn, does not get involved with others.	01	02	03
s74.	Breaks things on purpose, deliberately destroys (his/her) own or others' things.	01	02	03
s75.	Clings to adults.	01	02	03
S76.	Cries too much.	01	02	03
s77.	Demands a lot of attention.	01	02	03
S78.	Is too dependent on others.	01	02	03
s79.	Feels others are out to get (him/her)	01	02	03
S80.	Hangs around with kids who get into trouble.	01	02	03
S81.	Is secretive, keeps things to (himself/herself).	01	02	03
S82.	Worries too much.	01	02	03

NOTE: QUESTIONS **S1.b-S50** AND **S51.b-S82** ARE ADAPTED FROM THE 1981 NH18 CHILD HEALTH **SUPPLEMENT**.

T. INCOME SUPPORT

Supplemental Security Income

(S) T1. a. Do you (Does PERSON) receive any SSI (Supplemental Security Income) payments from the U.S. Government?

* Y E S 0 1

NO00 (SKIP TO Q.T2)

DON'T KNOW -1 (SKIP TO Q.T2)

(S) b. Do you (Does PERSON) have a representative payee? (Is someone else's name also on the check?)

* Y E S 0 1

NO00

DON'T KNOW -1

Social Security

T2. a. Do you (Does PERSON) receive any Social Security payments?

Y E S 0 1

NO00 {SKIP TO Q.T3}

DON'T KNOW -1 (SKIP TO Q.T3)

(S) b. Do you (Does PERSON) have a representative payee? (Is someone else's name also on the check?)

*YES...01

NO 0 0

DON'T KNOW -1

(S) c. What is the reason you are (PERSON is) getting Social Security?

CIRCLE ONE

RETIRED.01 (SKIP TO Q.T2.e)
DISABLED02
WIDOWED OR SURVIVING CHILD03 (SKIP TO Q.T2.e)
SPOUSE OR DEPENDENT CHILD.04 (SKIP TO Q.T2.e)
*ADULT DISABLED IN CHILDHOOD.05 (SKIP TO Q.T2.e)
OTHER (SPECIFY).06 (SKIP TO Q.T2.e)

DON'T KNOW-1 (SKIP TO Q.T3)

(S) d. At what age did you (PERSON) begin receiving Social Security because of your (his/her) disability?

!__!__! YEARS OLD

DON'T KNOW.-1 => PROBE: Was it before you were
(he/she was) 22 years
old?

*YES01
NO00
DON'T KNOW ... -1

e. Sometimes people get Social Security for more than one reason. Is there another reason you are (PERSON is) receiving Social Security?

YES0 1
NO00 (SKIP TO Q.T3)
DON'T KNOW-1 (SKIP TO Q.T3)

- (S) f. What is the other reason you are (PERSON is) getting Social Security?

CIRCLE ONE

RETIRED.01 (SKIP TO Q.T3)
DISABLED02
WIDOWED OR SURVIVING CHILD03 (SKIP TO Q.T3)
SPOUSE OR DEPENDENT CHILD.04 (SKIP TO Q.T3)
*ADULT DISABLED IN CHILDHOOD.05 (SKIP TO Q.T3)
OTHER (SPECIFY).06 (SKIP TO Q.T3)

DON'T KNOW -1 (SKIP TO Q.T3)

- (S) g. At what age did you (PERSON) begin receiving Social Security because of your (his/her) disability?

|_|_| YEARS OLD

DON'T KNOW -1 => PROBE: Was it before you were
(he/she was) 22 years
old?

*YES01

NO.00

DON'T KNOW. ... -1

Medicare

- T3. a. Medicare is a health insurance program for disabled persons and persons 65 or older. People covered by Medicare have a card that looks like this (SHOW CARD). Are you (Is PERSON) covered by Medicare?

YES.01

NO00 (SKIP TO Q.T4)

DON'T KNOW-1 (SKIP TO Q.T4)

- b. May I see your (PERSON'S) Medicare card to **record** the claim number and type of coverage?

Claim Number _____

Type of Coverage _____

Refused.-3

Card not available-5

(ASK: May I call you back when you have the card available? **GET** PHONE NUMBER AND SCHEDULE DATE AND TIME TO CALL.)

PHONE **NUMBER** _____

DATE AND TIME _____

- c. Medicare has an optional feature which costs extra and helps pay for doctor bills. Does your (PERSON'S) Medicare-help pay for doctor bills?

YES 0 1

NO0 0

DON'T **KNOW**-1

T4. a. Are you (Is PERSON) covered by (USE LOCAL NAME FOR MEDICAID) or another public assistance program that pays for medical care?

DON'T KNOW -1

T5. a. **INTERVIEWER:** IS PERSON AGE 18 OR OLDER?

NO. **.00** (SKIP TO Q.T5.c)

b. Are you (Is PERSON) authorized to receive food stamps? (An authorized person is the one whose name appears on a certification card.)

DON'T KNOW-1 (SKIP TO Q.T6.a)

c. Are you (Is PERSON) covered under someone else's food stamp allotment? (Does someone else in the house get food stamps to help buy food for you?)

DON'T KNOW -1

Other Public Assistance



T6. a. **INTERVIEWER:** IS PERSON AGE 18 OR OLDER?

YES01

NO00 (SKIP TO Q.T6.d)

b. (Other than what we have already mentioned), do you (does PERSON) receive any (other) welfare such as **AFDC** or General Assistance?

YES0 1

NO00 (SKIP TO Q.T6.d)

DON'T KNOW-1 (SKIP TO Q.T6.d)

c. What types of welfare do you (does PERSON) receive?

CIRCLE ALL THAT APPLY

A F D C01 (SKIP TO NEXT SECTION)

General Assistance02 (SKIP TO **NEXT** SECTION)

DON'T KNOW.-1 (SKIP TO NEXT SECTION)

d. Are you (Is PERSON) covered under someone else's welfare payment such as AFDC or General Assistance?

YES0 1

NO00 (SKIP TO **NEXT** SECTION)

DON'T KNOW.-1 (SKIP TO NEXT SECTION)

e. What kind of welfare does this other person receive?



General Assistance

U. FACILITIES MODULE: FORMAL STAFF SUPPORT

INTERVIEWER: IS THIS RESIDENCE CODED IN **Q.A5** AS:

02 GROUP HOME
03 HALFWAY HOUSE
04 PERSONAL CARE/BOARD AND CARE/BOARDING HOME
05 DEVELOPMENTAL CENTER
06 OTHER GROUP RESIDENCE/FACILITY?

YES. **.01**

NO00 (SKIP TO NEXT MODULE)

U1. Which one of these categories best describes the ownership of this (FACILITY/HOME)...

CIRCLE ONE

For profit (an individual, partnership,
or corporation) **.01**

Private nonprofit (religious group,
nonprofit corporation, etc.). **.02**

City/County government. **.03**

State government. **.04**

Federal agency (SPECIFY). **.05**

U2. How many beds in this (FACILITY/HOME) are regularly maintained for residents? **Please include** all beds staffed and set up for residents. Do not include beds used by staff or owners, or beds used only for day care patients or for emergency care.

BEDS

u3. Does this (FACILITY/UNIT) primarily or exclusively serve any of the following groups of persons...

CIRCLE ONE

Deaf	0	1
Blind	0	2
Mentally ill only03
Mentally ill and deaf04
Mentally retarded or developmental disabled only05
Mentally ill and mentally retarded.06
Other neurologically or physically handicapped07
Geriatric (elderly or aged)08
Some other special group (SPECIFY).00
<hr/>		
Does not serve one group primarily or exclusively.09
DON'T KNOW-1

- u3. a. Which one of these categories best describes this
(FACILITY/HOME/UNIT)...

CIRCLE ONE

State institution for mentally
retarded/developmentally disabled01

Foster home for mentally **retarded/DD**.02

Group residence for mentally **retarded/DD**. .03

Semi-independent living program for
mentally **retarded/DD**.04

Some other kind of place for mentally
retarded/DD (SPECIFY)05

Some other kind of place (SPECIFY).06

DON'T KNOW.-1

u4. In addition to room and board, does this (FACILITY/HOME/UNIT)
routinely provide...

CIRCLE ALL THAT APPLY

Nursing or medical care?.01

Supervision over residents who
administer their own medications?02

Help with bathing?.03

Help with dressing?04

Help with correspondence or shopping?05

Help with walking or getting about?06

Help with eating?07

Help with communication (such as hearing,-
speaking, sign language, or writing)? .. .08

Education or training programs?09

Other regular programs or activities?10

US. Does this (FACILITY/HOME/UNIT) provide 24-hour-a-day, **seven-day-a-**
week supervision of its residents?

Y E S 0 1

N O 0 0

DON'T KNOW. -1

U6. How many of the (INSERT # FROM Q.U2) beds in this (FACILITY/
HOME/UNIT) are licensed by the state health department or other
responsible state agency?

BEDS

(IF "NONE," ENTER "0" AND SKIP TO Q.U8)

u7. By which agencies are they licensed?

CIRCLE ALL THAT APPLY

AGENCY FOR THE MENTALLY RETARDED/
DEVELOPMENTALLY DISABLED.01

SOCIAL SERVICES02

HEALTH DEPARTMENT03

OTHER (SPECIFY)00

DON'T KNOW.-1

U8. Is this (FACILITY/HOME/UNIT) accredited?

YES0 1

NO.00 (SKIP TO Q.U10)

DON'T KNOW.-1 (SKIP TO Q.U10)

U9. By which organization is it accredited?

CIRCLE ALL THAT APPLY

JCAH (JOINT COMMITTEE OF ACCREDITATION
OF HOSPITALS.01

ACMRDD (ACCREDITATION COUNCIL ON MENTALLY
RETARDED AND DEVELOPMENTALLY DISABLED). . .02

CARF (COMMISSION ON ACCREDITATION OF
REHABILITATION FACILITIES).03

OTHER (SPECIFY)00

DON'T KNOW.-1

U10. Does the (FACILITY/HOME/UNIT) have any beds certified by Medicaid as ICF-MR (that is, Intermediate Care Facility for the Mentally Retarded) beds?

YES01

NO.00 (SKIP TO Q.U12)

DON'T KNOW.-1 (SKIP TO Q.U12)

U11. How many beds are certified under Medicaid as ICF-MR beds?

BEDS

u12. Does this (FACILITY/HOME/UNIT) have any beds certified by Medicaid as ICF (that is, Intermediate Care Facility) beds, excluding ICF-MR beds?

YES.....*01

NO.00 (SKIP TO Q.U14)

DON'T KNOW. -1 (SKIP TO Q.U14)

u13. How many beds are certified under Medicaid as ICF beds, excluding **ICF-MR** beds?

BEDS

u14. Does this (FACILITY/HOME/UNIT) have **any beds** certified by Medicaid as SNF (that is, Skilled Nursing Facility) beds?

Y E S 0 1

NO.00 (SKIP TO Q.U16)

DON'T KNOW. -1 (SKIP TO Q.U16)

U15. How many beds are certified under Medicaid as SNF beds?

BEDS

U16. Does this (FACILITY/HOME/UNIT) have any beds certified by Medicare as SNF beds?

Y E S 0 1

NO.00 (SKIP TO Q.U18)

DON'T KNOW. -1 (SKIP TO Q.U18)

u17. How many beds are certified under Medicare?

BEDS

U18. What type of physician services are available in this (FACILITY/
HOME/UNIT)?

CIRCLE ONE

PHYSICIAN(S) ON THE PREMISES AT
ALL TIMES01

PHYSICIAN(S) ON THE PREMISES AT
ALL TIMES DURING THE DAYTIME
HOURS EVERY WEEKDAY, AND ON-CALL
ON WEEKENDS AND AT OTHER TIMES.02

PHYSICIAN(S) ON THE PREMISES AT
SCHEDULED TIMES NO LESS THAN
ONCE PER MONTH AND ON-CALL THE
REMAINDER OF THE TIME03

PHYSICIAN(S) AVAILABLE ONLY ON-CALL04

OTHER (SPECIFY)00

U19. Does this (FACILITY/HOME/UNIT) have a waiting list of persons to be
admitted when a bed becomes available?

YES01

NO.00 (SKIP TO Q.U23)

DON'T KNOW.-1 (SKIP TO Q.U23)

U20. Is the waiting list for this (FACILITY/HOME/UNIT) only, or for other
(FACILITIES/HOMES/UNITS) as well?

THIS PLACE ONLY01

OTHERS AS WELL.02

DON'T KNOW.-1

u21. How many people are on this waiting list?

PEOPLE

DON'T KNOW. -1

u22. Are any services provided to people on this waiting list?

YES01

NO 0 0

DON'T KNOW. -1

U23. Next, I'd like to know about the numbers of paid or contracted staff who work here. Tell me how many full-time and how many part-time staff members of each type work at this (FACILITY/HOME/UNIT). If you prefer, you may answer in full-time equivalents.

	<u>FULL-TIME</u>	<u>PART-TIME</u>	<u>OR, FTE</u>
a. Physicians, including residents and interns? ..	# _____	# _____	# _____
b. Registered nurses (RNs)?.....	# _____	# _____	# _____
c. Licensed practical or vocational nurses (LPNs, LVNs)?	# _____	# _____	# _____
d. Nurses' aides/orderlies?	# _____	# _____	# _____
e. Physical therapists?	# _____	# _____	# _____
f. Occupational therapists?	# _____	# _____	# _____
g. Psychologists?	# _____	# _____	# _____
h. Social workers?.	# _____	# _____	# _____
i. Speech or language pathologists?	# _____	# _____	# _____
j. Audiologists?.	# _____	# _____	# _____
k. Recreation/activities staff?	# _____	# _____	# _____
l. Teachers certified/licensed by the state?. . . .	# _____	# _____	# _____
m All other care staff?.	# _____	# _____	# _____

U24. I am also interested in learning about persons who provide services on a voluntary basis at least once a week here--that is, they are not paid to provide services. Do you have any such regular volunteers?

YES01

NO.00 (SKIP TO NEXT MODULE)

DON'T KNOW.-1 (SKIP TO NEXT MODULE)

U25. Approximately how many hours during a typical week do volunteers presently spend at this (FACILITY/HOME/UNIT)?

VOLUNTEERS

V1. TYPE OF HOUSING UNIT/STRUCTURE

DUPLEX OR ROW HOUSE.02

APARTMENT BUILDING03

MOBILE HOME OR TRAILER04

V2. A. NUMBER OF BEDROOMS 1- 1 1

DON'T KNOW-1

B. IS THERE A SEPARATE BEDROOM FOR **EACH** PERSON?

YES. 0 1

NO 0 0

DON'T KNOW -1

V3. A. NUMBER OF PUBLIC ROOMS | - - I - |

DON'T KNOW-1

B. PURPOSE OF PUBLIC ROOMS

DON'T KNOW-1

v4. HEALTH/SAFETY PROBLEMS

	<u>YES</u>	<u>NO</u>	<u>DON'T KNOW</u>
LOOSE OR SHAKY STAIRS	01	00	-1
BROKEN WINDOWS.	01	00	-1
LACK OF SECURE LOCKS ON EXTERIOR DOOR . .	01	00	-1
UNSAFE HEATING.	01	00	-1
UNSAFE LIGHTING/BARE WIRES.	01	00	-1
ACCUMULATION OF TRASH IN OR AROUND RESIDENCE	01	00	-1
RATS/MICE OR THEIR DROPPINGS.	01	00	-1
STRONG ODOR OF EXCREMENT.	01	00	-1
INSIDE FLOODING OR STANDING WATER	01	00	-1
BUGS/INSECTS.	01	00	-1
OTHER (SPECIFY)	01	00	-1

VS. EXTERIOR OF RESIDENCE:

DISTINCTLY DIFFERENT FROM REST OF
NEIGHBORHOOD--NUMBER OF EXTERNAL
SIGNS/FEATURES THAT RESIDENCE IS
A "GROUP HOME"01

MINIMALLY DIFFERENT FROM REST OF
NEIGHBORHOOD02

NOT DISTINCTLY DIFFERENT; LOOKS LIKE
REST OF NEIGHBORHOOD03

NOT APPLICABLE--RESIDENCE IS ON CAMPUS
OF A LARGE, CONGREGATE FACILITY.04

DON'T KNOW -1

V6. WHAT OTHER TYPES OF BUILDINGS ARE IN THE NEIGHBORHOOD?

SINGLE FAMILY HOMES.01
MULTIPLE HOUSEHOLD UNITS02
MIXED SINGLE AND MULTIPLE
HOUSEHOLD UNITS.03
PREDOMINANTLY STORES04
FACTORIES AND LARGE BUSINESSES05
CAMPUS BUILDINGS06
LOCATED ON GROUNDS OF AN INSTITUTION
OR CENTER.07
OTHER (SPECIFY).08

DON'T **KNOW**-1

v7. PRIMARY RESPONDENT

INDIVIDUAL SAMPLE MEMBER01 (END)
PROXY (SPECIFY RELATIONSHIP)02

V.8 WAS INDIVIDUAL SAMPLE MEMBER PRESENT DURING THE INTERVIEW?

Y E S 0 1
N O00

V.9 DID INDIVIDUAL SAMPLE MEMBER PARTICIPATE (PROVIDE INFORMATION) IN THE INTERVIEW?

ANSWERED VERY FEW OR NONE OF
THE QUESTIONS.01

ANSWERED FEWER THAN HALF THE QUESTIONS . .02

ANSWERED ABOUT HALF THE QUESTIONS.03

ANSWERED MORE THAN HALF THE QUESTIONS. . .04